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ABSTRACT

This trainer's manual was developed to provide a consistent knowledge and skill base (i.e., a "foundation") for all individuals employed in programs funded by Oklahoma's Developmental Disabilities Services Division. They include van drivers, recreation workers, residential staff, administrators, case managers, secretarial/clerical staff, vocational staff, advocates, physicians, psychologists, and others. The goal is to create an environment in which all people with developmental disabilities are valued and treated as normally as possible. The training is composed of four modules of instruction: (1) "People Are People" defines developmental disability and describes some of the disabilities included in that term; (2) "Changing Times" traces historical events that influenced how services for people with developmental disabilities developed, emphasizes an understanding of what didn't work and why, and introduces the principle of normalization; (3) "Systems and Policies" provides a snapshot of the Oklahoma service delivery system, including public and private service providers, families, advocates, and others; and (4) "The New Frontiers" offers a vision of the future and examines technological trends. Instructional methods include large and small group activities; the use of videos, transparencies, and other audiovisual media; handouts; and exercises. The manual provides camera-ready masters for making transparencies. (Contains 30 references.) (JDD)

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ED 374 583

# Foundation Level Training

## Trainer's Manual

Department of Human Services
Developmental Disabilities
Services Division

EC 303303

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# Department of Human Services
# Developmental Disabilities Services Division

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and

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Epilepsy Clinical Research Program, Department of Neurology, Medical School at the University of Minnesota, Twin Cities Campus, Suite 255, 5775 Wayzata Boulevard, Minneapolis, MN 55416-1222, for their video ***Epilepsy: A Positive I.D.***.

The Governor's Planning Council on Developmental Disabilities, Minnesota Department of Administration, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155; and the Minnesota University Affiliated Program, St. Paul, MN, for the use of their video ***A New Way of Thinking.***

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The World Future Society, 7910 Woodmont Avenue, Suite 450, Bethesda, MD 20814, for the use of their articles ***Enabling the Disabled*** and ***The Mind- Reading Computer*** in The Futurist, May-June 1992.

The Avocado Press, Box 145, Louisville, KY 40201, for the use of the article ***The Hierarchy of Acceptance***, in The Disability Rag, March/April 1992.

A Prairie Home Companion, Department G.B., Minnesota Public Radio, 45 East 8th. St., St. Paul, MN, for the use of their audio cassette ***Donny At The Bus Stop.***

Apple Computers, Educational Support, 2424 Ridgepoint Drive, Austin, TX 78754, for the use of their video ***Chapter One.***

The Learning House, 1548 Cherokee Rd., Louisville, KY, 40205, for the use of their audio cassette ***The Exceptional Parent Blues.***

20/20, Audience Information, 77 West 66th., 9th. Floor, New York, NY, for the use of their program ***Rumania's Children.***

# FOUNDATION TRAINING

## Trainer Introduction

Foundation training was developed to meet the primary training needs of staff, individuals, and families working with people with developmental disabilities. The principal objectives for the Foundation Level training course are to:

- Provide all staff with a shared vision of what Oklahoma's system of services will look like.
- Provide a consistent information, knowledge, and skill base for all individuals who serve people with developmental disabilities.
- Prepare staff to become more effective members of the teams that provide assessment, planning, and the delivery of services for individuals with developmental disabilities.
- Improve the quality of communication and social interaction skills of staff who provide services.
- Provide a functional definition of developmental disabilities and help staff understand common types of developmental disabilities.
- Provide an understanding of historical issues influencing individuals with developmental disabilities and how they influence today's attitudes.
- Provide staff and individuals with an understanding of the Principle of Normalization.
- Provide a philosophy of services that is consistent with current state and national trends in service delivery.
- Provide staff and individuals with a better awareness of the individual's with developmental disabilities rights and legal issues surrounding service delivery.
- Provide staff and individuals with an understanding of the services available within the State of Oklahoma and specifically, through the Developmental Disability Services Division.
- Provide an understanding of mistreatment\maltreatment, reporting measures for suspected abuse and neglect, and the importance of the use of non-aversive techniques.

- Provide an introduction to future technological trends that may influence the quality of life of individuals with developmental disabilities.
- Provide an awareness of the role of the State and the Statement of Beliefs that influence the State in its performance of services for individuals with developmental disabilities.

### *Who will receive training?*

Foundation training is being provided to all public or private employees who are, or who will be employed full-time in programs funded by the Developmental Disabilities Services Division. It is mandatory for those employees, and it is hoped that it can be made available to families and private citizens (on an "as space is available" condition).

### *Who will attend?*

Van drivers
Recreation workers
Residential Staff (institution and community)
Administrators
Case Managers
Secretarial/Clerical staff
Vocational staff
Advocates
Physicians
Psychologists
Etc.

### *Why is it mandatory?*

- So that all people with developmental disabilities and their families can expect the same high quality of service, no matter where they live in our state.
- So that managers can reinforce what their employees were taught.
- So that everyone shares a common values base and is able to integrate those beliefs into practical applications.

- So that community-based service employees, who are often dispersed and may not have ready access to fellow workers or supervisors, can have an indication of what their employers expect them to do in a given situation.
- So that the thousands of people employed in the service system (along with thousands more of their friends and relatives) can help to support positive societal attitudes. (There have been experiences in the past few years when such unity would have been helpful to offset negative images presented in the press or in legislative chambers.)

## STRUCTURE OF THE TRAINING

**Five levels of training:**

- Foundation Level - (before starting work)
- Job Specific - (to begin 30 days after Foundation Level is completed)
    - Residential
    - Vocational
    - Case Manager
    - Support Staff
    - Administrative
- Specialized Needs Training - (only for those who will be workings with these clients)
    - Behavioral
    - Physical
- Client Specific - (this will provided on-site and will be based on the IHP)
- On-going Annual In-Service Training
    - Refreshers
    - Introduction of New Material

NOTE:

- Foundation Level training - required of all new employees as noted above.
- Job Specific training (residential, vocational, case management, administration, and support staff) - non-direct service employees such as van drivers and clerical staff will not go through job specific training.

# ISSUES

**GOALS:** This training does not dwell on issues such as productivity and independence as does most traditional training material. This is not to deny the importance of helping people to maximize potential; however there has been a tendency to view people as valued only in relation to their productivity and potential for independence. A theme that will be repeated throughout the training is that people have value simply because they are people. If they are a persons with very severe disabilities and may thus require lifelong support, they are not to be diminished because of the dependency. While we are proud of what some people can accomplish and how effective our work may be in helping them to be more productive and independent, that is not our primary goal. Our goal is ecological, to create an environment in which all people with developmental disabilities are valued and treated as normally as possible.

**GROUP COMPOSITION:** It is intended that the training groups will be as heterogeneous as possible. We believe that there is value in having direct service staff in the same classroom with professionals. We think it is important, when possible, to have people who work in institutional settings and sheltered workshops in the same classrooms as people who work in the newly emerging community settings.

**MODELS VERSUS PEOPLE:** It is also important to constantly emphasize that when we discuss traditional models of service delivery, e.g. institutions and sheltered workshops, and when we are critical of those models, a clear distinction is made between criticizing the model but not criticizing the people who work in those models. Every effort has been made to make that distinction in this training. But, it is very important for the trainer be sensitive to those issues.

**ATTITUDES:** Trainees sometimes leave training classes and go to work, only to discover that their employers or co-workers are doing the "wrong" things. There are two dangers here. First, the new employee can be co-opted by old timers and convinced that what they were taught was idealistic or not possible. Or, inversely, the employee can alienate others by assuming attitudes that may result in misconceptions and ill will. It will be important for the trainees to understand that when they go to their places of employment, their fellow workers may not understand the values that the new employee has been trained in. The less-than-progressive methodologies in existence that are described in this training may be exactly what the trainee finds when they go on the job. It is important for trainers to discourage trainees from feeling superior or "holier-than-thou" with their fellow employees (for obvious reasons). It is also important to note that we hope to bring employees who were trained under the old training materials through this training.

**PLAIN ENGLISH, JARGON, AND ACRONYMS:** Coming into the field of developmental disabilities as a new employee can be a very heady experience. One gets to learn about new ways of looking at the world; new ideas and values as well as new attitudes. We're part of an exciting social movement that in many ways is like the civil rights movement of the fifties and sixties. Even the language that gets used is foreign. Words, phrases, and terms that stand for other things -- IHP's, DHS, DDSD, the Arc, etc., and medical and clinical terms like PKU, phenylketonuria, meningomyocele, clonic-tonic, etc. -- seem like an entire new language at times.

It is common for those of us who have been in the field for a long time to use such terms without even thinking about them. It is also common for new employees to want to experiment with those same terms; to try them out on friends and family. Most of us did the same thing when we first started.

Sometimes, new employees who are feeling a little insecure and anxious about their competency, especially if they're working around co-workers who have had a medical model type of training experience, will use jargon and acronyms with parents or people with disabilities. Their intent is to send the message: "I'm competent. I know what I am doing. Trust me." Unfortunately, the message that gets received is: "What is she talking about? I don't want to look stupid so I'll just nod my head, smile, and pretend I understand." Worse, many parents who have been knocking around in this field for years and years know more than the professionals about their son's or daughter's particular condition, and they aren't at all impressed.

To the maximum extent possible, this training material is written in plain english.

If we can use a one syllable word rather than a two, three, or four syllable word, we do. Please emphasize with the students that we want them to learn "the language," but we also value good, honest communication between us and the people we serve. Explain that the use of jargon, acronyms and technical language puts distance between us and those we serve, as well as between us as advocates and the public at large.

## MODULES

Foundation Training is composed of four modules of instruction:

- **Module One - "People Are People"**
  Defines the term, developmental disability, and describes some of the disabilities included in that term. Emphasis is placed on the concept of looking at individuals as *people rather than products of their disability.*

- **Module Two - "Changing Times"**
  Traces the historical events that influenced how services for people with developmental disabilities developed and emphasizes an understanding of what didn't work and why it didn't work so that we don't repeat the mistakes of the past. Also introduces the Principle of Normalization and the importance of role models.

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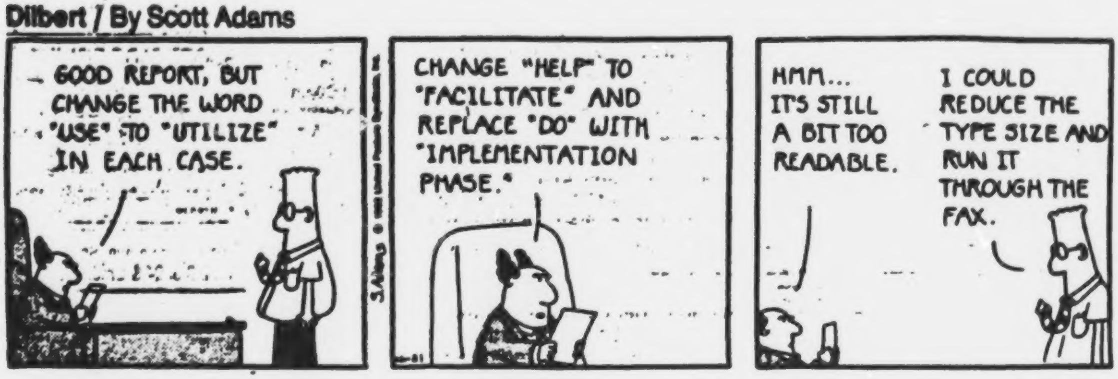
GOOD REPORT, BUT CHANGE THE WORD "USE" TO "UTILIZE" IN EACH CASE.
CHANGE "HELP" TO "FACILITATE" AND REPLACE "DO" WITH "IMPLEMENTATION PHASE."
HMM... IT'S STILL A BIT TOO READABLE.
I COULD REDUCE THE TYPE SIZE AND RUN IT THROUGH THE FAX.

Dilbert / By Scott Adams

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- **Module Three - "Systems And Policies"**
  A snapshot of the State of Oklahoma service delivery system today, including public and private service providers, families, advocates, etc. Reaffirms the importance of individuals who work most closely with people with developmental disabilities.

- **Module Four - "The New Frontiers"**
  Provides a "Vision of the Future". It is a blueprint which logically emerges from the previous three modules. It is vitally important that all of us share the vision and focus our energies in the same direction. It also provides a look at future technological trends that may influence the lives of individuals with developmental disabilities.

## METHODS

The use of a variety of instructional methods will prevent boredom and encourage fuller participation. Group participation is highly encouraged as this promotes the sharing of information, exchange of ideas, and development of questions as well as aiding in the development of group cohesiveness and content clarity. Large group discussions can be conducted over generalized categories of information. Smaller groups (3-6) individuals can discuss information and present to larger groups as another exercise. Remember, adults like to be in charge of their own learning environment. Give them this opportunity as much as possible by using large and small group methods of participation. Video tapes, audio cassettes, overhead transparencies, and other aids are provided to help meet a variety of learning styles. In addition, trainers are encouraged to use their own creativity as long as the module objectives are accomplished.

Two methods are used to alert the trainer to media, exercises, and discussions and their placement within the text. Media, as well as major text titles are placed in the right hand "Trainer Information" column. The major body of information and textual materials are placed in the left hand column. "Trainer Notes" are placed within this text information to alert the trainer to placement of media, exercises, activities, discussions, etc.

At the end of each major section of information, an "Instructor Questions" segment will present questions that the trainer can use to stimulate group questions or as a review and summary of information.

# ICONS

The following icons are located in the text to alert the trainer to the placement of media and activities:

Transparency
Handout

Video
Cassette

Activity
Exercise

# SUPPLEMENTAL INFORMATION AND ACTIVITIES

Included at the back of each module is a section for supplemental information. This includes handouts that may not be in the trainer's manual as well as optional transparencies for that module. It also include instructions for activities and exercises presented earlier in the module.

The trainer is encouraged to add his or her own materials to this section for use during training as long as the objectives are met and content of the module is not changed. Variety aids adults in the learning process, you are encourage to supply this variety as you find it.

## TRAINING CLIMATE

The following guidelines are suggested for the creation of a positive training climate:

*Considering Adult Learning Characteristics*

1. Consider the relevance of the topic to the daily tasks of the learners.
2. Capitalize on the high motivational level of adult learners.
3. Consider the need for involvement in the training process.
4. Consider the desire for variety.
5. Consider the need for positive feedback.
6. Recognize that adult learners often have concerns about their learning abilities.
7. Treat adults as individuals.

*Planning for a Positive Training Climate before Instruction*

1. Conduct an audience profile.
2. Conduct topic research.
3. Select an appropriate instructional strategy for the topic.
4. Develop or review the presentation plan.
5. Consider the needs of the participants.
6. Examine the physical training facilities, including the classroom and the arrangement of furniture.

*Establishing and Maintaining a Positive Training Climate during Instruction*

1. Use an effective delivery style.
2. Utilize good verbal communication skills, i.e., communicating on a personal level, emphasizing important points, using work-related examples.
3. Utilize good nonverbal communication skills, i.e., maintaining eye contact, making effective gestures, moving about the room, using effective visuals.
4. Employ questioning and reinforcement skills.
5. Employ the use of humor, where appropriate.

*Providing a Positive Training Climate after Instruction*

1. Be accessible before the training session begins.
2. Be assessible at the end of each training session.
3. Provide follow-up assistance in the work place.

*Considering the Challenges of Training Adults with Special Needs*

Working with Individuals with Emotional Problems

1. Be consistent in standards and expectations.
2. Be concerned with learners as individuals.
3. Offer positive reinforcement.
4. Utilize individualized instruction.
5. Build on previously mastered tasks.

Working with Individuals with Visual Handicaps

1. Employ the use of adjustable desk tops or tables.
2. Utilize talking calculators, magnifiers, or special lighting.
3. Utilize auditory warning devices on equipment and machinery.
4. Utilize materials written in Braille.

Working with Individuals with Hearing Impairments

1. Seat learners near the front of the room.
2. Seat learners in the best lighting conditions.
3. Repeat information if it is not understood.
4. Have learners explain new material after it is introduced, to determine comprehension.
5. Maintain eye contact.
6. Employ the use of visuals.

Working with Individuals with Learning Disabilities

1. Utilize the learner's strongest learning channel.
2. List instructions and directions on the writing board.
3. Use individualized instruction techniques.
4. Provide learners with an outline of each session.

Working with Individuals with Communication Problems

1. Model correct sentence structure.
2. Maintain eye contact when communicating.
3. Do not force learners to give oral reports until they are ready.
4. Utilize small group activities.
5. Allow students sufficient time to complete sentences.

Working with Individuals with Health Problems

1. Arrange for convenient seating.
2. Use individualized and programmed instructional materials when appropriate.
3. Allow learners to work on tasks at their own pace.
4. Identify special materials, equipment, or aids that will meet the needs of the learner adequately.
5. Tape training sessions for learners' use.

Working with Individuals with Physical Disabilities

1. Seat learners where they will be the most comfortable.
2. Utilize peer volunteers.
3. Utilize the suggestions of physically disabled learners in making adaptations to the training facility, equipment, and machinery.
4. Place materials and supplies on lower shelves.
5. Allow learners to tape assignments and tests.

Working with Individuals with Cultural Differences

1. Provide learners with key terms before each training session.
2. Be tolerant of differences in cultural backgrounds.
3. Encourage learners to bring dictionaries to training sessions.
4. Utilize hands-on experiences whenever possible.
5. Speak slowly and use simple vocabulary and grammar.
6. Adjust the length of assignments.
7. Help the learner to establish realistic short-term and long-term goals.
8. Modify instructional techniques to the style and rate of learning of each learner.

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# MEDIA AND EXERCISES

## *MODULE ONE - "PEOPLE ARE PEOPLE"*

### Equipment:

- VCR\Television
- Cassette Player
- Overhead Projector
- Flip Chart and Markers (if desired)

### Videos:

- "Epilepsy: A Positive I.D."
- "A New Way of Thinking"

### Transparencies:

- 1.1 - John Is...
- 1.2 - John Is...
- 1.3 - A Developmental Disability is...
- 1.4 - Seven Major Life Areas
- 1.5 - Functional Definition
- 1.6 - Mental Retardation
- 1.7 - Causes of Mental Retardation
- 1.8 - Prenatal and Perinatal Causes
- 1.9 - Postnatal Causes
- 1.10 - Epilepsy
- 1.11 - Cerebral Palsy
- 1.12 - Autism
- 1.13 - Statistics

### Handouts:

- 1A - You and I
- 1B - It's the People First
- 1C - Using Language Appropriately
- 1D - Tips on Writing
- 1E - Facts
- 1F - Oklahoma Statistics

**Activities:**

- "Alphabetizing"
- "Airplane Toss"

**Exercises:**

- "Using People First Language"
- "Definition"

## *MODULE TWO - "CHANGING TIMES"*

**Equipment:**

- VCR\Television
- Cassette Player
- Overhead Projector
- Flip Chart and Markers (if desired)
- Ball of String

**Videos:**

- "Willowbrook"
- "Rumania's Children"
- "Clangers"
- "Americans With Disabilities" (optional)

**Audio - Visual Media:**

- Cassette - "Donny at the Bus Stop"

**Transparencies:**

- 2.1 - Historical Outline
- 2.2 - Role Perceptions
- 2.3 - Misconceptions
- 2.4 - Closures (Bar Graph)
- 2.5 - Population (Line Graph)
- 2.6 - Congregation
- 2.7 - Lack of Contact

**Transparencies: (cont.)**

- 2.8 - Segregation...
- 2.9 - Rehabilitation Act
- 2.10 - IDEA
- 2.11 - Developmental Disabilities...Act
- 2.12 - Mistreatment
- 2.13 - Physical Abuse
- 2.14 - Sexual Abuse
- 2.15 - Emotional Abuse
- 2.16 - Exploitation
- 2.17 - Neglect
- 2.18 - General Rules
- 2.19 - Values
- 2.20 - Misconceptions
- 2.21 - Social Integration
- 2.22 - Tips

Handouts:

- 2A - The Parent Experience
- 2B - Wasting Away in Oklahoma
- 2C - State Schools
- 2D - Hissom Client/Consent Decree
- 2E - Closures and Projected Closures
- 2F - Enlightening Principle of Normalization

DHS Publications

- 2A.1 - 86.150 Health Care
- 2A.2 - 91-10 Signs of Mistreatment

Activities

- "String Toss"

Exercises

- "Reasons"
- "Rights"
- "The Holiday Incident"

# *MODULE THREE - "SYSTEMS AND POLICIES"*

**Equipment:**

- VCR\Television
- Overhead Projector
- Flip Chart and Markers (if desired)
- Blindfolds

**Videos:**

- "Choices - Residential Options"
- "A Change of Seasons"

**Audio - Visual Media:**

- Cassette - "The Exceptional Parent Blues"

**Transparencies:**

- 3.1 - Service System
- 3.2 - Funding Sources
- 3.3 - Federal Government
- 3.4 - Organization Chart (Federal)
- 3.5 - Organizational Chart (State)
- 3.6 - State Departments
- 3.7 - State Departments
- 3.8 - State Departments
- 3.9 - Advocacy
- 3.10 - Advocacy Groups
- 3.11 - Continuums
- 3.12 - Residential Services
- 3.13 - In-Home/Out-Of-Home Services
- 3.14 - Vocational Services
- 3.15 - Support Services
- 3.16 - Elements of a Good Program
- 3.17 - Developing the Plan

**Handouts:**

- 3A - State Definitions
- 3B - DDSD Area Offices
- 3C - Resource Directory
- 3D - Rehabilitation Offices
- 3E - Waiver Services
- 3F - Acronym Guide

DHS Publications
- 3A.1 - 88.23 Overview of DDS
- 3A.2 - 86.17 Myth vs. Reality
- 3A.3 - 86.119 A Guide to Support Services
- 3A.4 - 88-18 Programs and Services/DHS Umbrella
- 91.61 DHS Programs Directory (optional for trainers)

Activities

- "Speakers" (optional)

## *MODULE FOUR - "THE NEW FRONTIERS"*

**Equipment:**

- VCR\Television
- Overhead Projector
- Flip Chart and Markers (if desired)

Videos:

- "The ARC - Self Advocacy"
- "Chapter One - Apple Computer"

**Transparencies:**

- 4.1 - Statement of Beliefs
- 4.2 - Self Advocacy

- 4.3 - Support, Not Supplant
- 4.4 - Matrix
- 4.5 - Technological Devices
- 4.6 - Our Task

**Handouts:**

- 4A - Speak For Themselves/A Vision
- 4B - Advocacy Situations
- 4C - Enabling the Disabled
- 4D - Integrated Lifestyle

**Group Exercises:**

- "Self-Advocacy Role Plays"
- "Participant Menu"

# *References, Suggested Readings, and Media Reviews...*

Apple Computers. *Chapter One.* Educational Support, 2424 Ridgepoint Drive, Austin, TX.

This video provides a view of future trends in technology that may affect the lives of people with disabilities.

The Arc. *Self Advocacy: Supporting the Vision.* Department of Research and Program Services, 500 E. Border Street, Suite 300, Arlington, TX.

This video focuses on the importance of self advocacy in the lives of people with disabilities.

The Avocado Press. The Hierarchy of Acceptance. *The Disability Rag.* March/April 1992.

Article addresses the acceptance of individuals with disabilities by society.

Baker, M.J., & Salon, R.S. (1986). Setting free the captives: The power of community integration in liberating institutionalized adults from the bonds of their past. *The Journal of the Association for Persons with Severe Handicaps, 11,* 179-181,

Vignettes describing the behavioral changes in more integrated environments are examined along with a discussion of implications for programs.

Brooks, D., et. al. (1990). *Vocational and Supported Employment.* DHS: The University of Oklahoma at Norman, OK.

This training program offers an extensive look at the development and management of supported employment programs.

Emerson, E.B. (1985). Evaluating the impact of Deinstitutionalization on the lives of mentally retarded people. *American Journal of Mental Deficiency, 90,* 277-288.

Article discusses deinstitutionalization and its effects on people who have severe mental retardation.

Epilepsy Clinical Research Program. *Epilepsy: A Positive I.D.* Department of Neurology, Medical School at the University of Minnesota, Twin Cities Campus, Suite 255, 5775 Wayzata Boulevard, Minneapolis, MN.

This video addresses issues concerning epilepsy, causes, conditions and symptoms.

Governor's Planning Council on Developmental Disabilities. (1987). *A New Way of Thinking.* GPCDD, 300 Centennial Building, 658 Cedar St., St. Paul, MN 55101.

Videotape and accompanying booklet discusses new ways of thinking concerning people with developmental disabilities. Although some statistics focus on Minnesota, most information has wide applications to the field of disabilities.

Keeler, G. *Donny At the Bus Stop.* A Prairie Home Companion, Department G.B., Minnesota Public Radio, 45 E. 8th. St., St. Paul, MN.

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Article focuses on the differences in the lives of a person with disabilities and a person without disabilities.

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This article answers questions concerning mental retardation and mental illness.

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This video focuses on the conditions in the Willowbrook institute in New York.

Sagona, W., et al. (1993). *Individual Habilitation Planning*. DHS: East Central University at Tahlequah, OK.

This training program addresses the process of successfully developing and instituting the Individual Habilitation Plan.

Sand Springs Leader. *Removed from shelter, Hissom client feels free.* Reprint, July 3, 1991.

Article concerning independent living status of Susie Meech, a person with mental retardation.

Taylor, S.J. (1982). From segregation to integration: Strategies for integrating severely handicapped students in normal school and community settings. *The Journal of the Association for the Severely Handicapped, 7(3),* 42-49.

A summary of strategies for successfully integrating school aged children. Information can be generalized to adult populations.

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This training program provides information on specific behavior management techniques as well as supplies trainer information on instructional methods for use in behavior building.

The Tulsa Tribune. *Wasting away in Oklahoma: A special report.* Reprinted series published Oct.1-10, 1984.

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Turnbull, H.R., Turnbull, A.P., Bronicki, G.J., Summers, J.A., & Roeder-Gordon, C. (1989). *Disability and the family: A guide to decisions for adulthood.* Paul Brookes: Baltimore, MD.

This book gives practical suggestions for families as they work with their children in making decisions for future goals.

Twenty/Twenty. *Romania's Children.* Audience Information. 77 West 66th., 9th. Floor. New York, NY.

This video program provides a view of institutions in Romania that house people with developmental disabilities.

University Affiliated Programs of Oklahoma. (1992-1993). *Statistics on developmental disabilities in Oklahoma.* UAP of Oklahoma Database.

Gives population statistics for individuals with developmental disabilities.

Wehman, P., Moon, M.S., Everson, J.M., Wood, W., & Barcus, J.M. (1988). *Transition from school to work: New challenges for youth with severe disabilities.* Baltimore: Paul H. Brookes.

Addresses issues related to preparing adolescents in public school programs for work as well as program planning and development of successful employment placements.

Wolfensberger, W. (1972). *The principle of normalization in human services.* Toronto, Canada: National Institute on Mental Retardation, York University Campus.

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1

MODULE ONE

# Foundation Level Training

## People are People

Department of Human Services
Developmental Disabilities
Services Division

# PEOPLE ARE PEOPLE

## Module One

# OBJECTIVES

## Module One

# PEOPLE ARE PEOPLE

Module 1 - Foundation Training

## LEARNING OBJECTIVES

***Primary Objective:*** Upon completion of this training and given the appropriate materials, the participant will be able to understand and apply the concept of looking at individuals with developmental disabilities as *people rather than as products of their disability.*

***Secondary Objectives:***

- Define and be able to use People First language. Discuss how the application of labels affects the lives of individuals with developmental disabilities.
- Identify the criteria involved and write a functional definition of the term "Developmental Disability."
- Describe common conditions leading to developmental disabilities and write a brief description of each.
- List three statistics concerning people with developmental disabilities.

# Training Information And Schedules

## Module One

# Training Schedule

## *MODULE 1 - PEOPLE ARE PEOPLE*

| Objectives | Key Points | Exercises/ Activities | Transparencies | Handouts | Media | Length |
|---|---|---|---|---|---|---|
| 1. Define and be able to use People First language. Discuss how the application of labels affects the lives of individuals with developmental disabilities. | • Types of labels<br>• "People First" language | • Alphabetizing (labeling)<br>• Airplane Toss<br>• Using People First Exercise | 1.1 John Is...<br>1.2 John Is... | 1A You and I<br>1B It's The Person...<br>1C Using Language...<br>1D Tips on Writing... |  | 1 hr/35 min. |
| 2. Identify the criteria involved and write a functional definition of the term "developmental disabilities." | • Evolution of term<br>• Characteristics of a developmental disability<br>• Seven major life areas<br>• Functional definition | • Definition Exercise | 1.3 Developmental Disability is...<br>1.4 Seven Major Life Areas<br>1.5 A Functional Definition |  |  | 1hr/15min |
| 3. Describe common conditions leading to developmental disabilities and write a brief description of each. | • Mental Retardation<br>• Epilepsy<br>• Cerebral Palsy<br>• Autism<br>• Other conditions |  | 1.6 Mental Retardation<br>1.7 Causes<br>1.8 Pre and Perinatal Causes<br>1.9 Postnatal Causes<br>1.10 Epilepsy<br>1.11 Cerebral Palsy<br>1.12 Autism | 1E Facts | Video: "Epilepsy: A Positive I.D." | 2hr |
| 4. List three statistics concerning people with developmental disabilities. | • Oklahoma statistics<br>• National statistics |  | 1.10 Oklahoma Statistics | 1F Oklahoma Statistics | Video: "A New Way of Thinking | 45min |

# People Are People

## MODULE OUTLINE

**I. LABELS AND PEOPLE FIRST LANGUAGE**

- A. PREJUDICE AND MISCONCEPTIONS
  - 1. Dehumanizing
    - a. First words spoken
    - b. Imply homogeneity

- B. GRAMMATICALLY INCORRECT
  - 1. Language Exercise

**II. FUNCTIONAL DEFINITION OF DEVELOPMENTAL DISABILITY**

- A. EVOLUTION OF TERM
  - 1. Funding
  - 2. Needs Met

- B. CHARACTERISTICS
  - 1. Prerequisites
    - a. Seven major life areas
    - b. Umbrella term

- C. FUNCTIONAL DEFINITION
  - 1. Eligibility
  - 2. Disabilities That Do Not Qualify
  - 3. Provide Only What Is Needed
  - 4. Not Synonymous

**III. DISCRIPTIONS OF COMMON CONDITIONS LEADING TO DEVELOPMENTAL DISABILITIES**

- A. MENTAL RETARDATION
  - 1. Key Elements
  - 2. Causes

        - a. Prenatal
        - b. Perinatal
        - c. Postnatal
    - 3. Support Required
        - a. Minimal
        - b. More intensive
        - c. Labeling and support of children

- B. EPILEPSY
    - 1. Key Elements
    - 2. Percentages
    - 3. Predisposition
    - 4. Medication

- C. CEREBRAL PALSY
    - 1. Key Elements
    - 2. Causes
    - 3. Technological Aids

- D. AUTISM
    - 1. Key Elements
        - a. Perception difficulties
    - 2. Causes
        - a. Parenting

- E. OTHER CONDITIONS
    - 1. Environments That Disable
        - a. Power of the environment

## IV. STATISTICS

- A. NUMBERS SERVED
    - 1. Percentages
    - 2. Numbers Served In Oklahoma
    - 3. National Statistics

# LECTURE AND ACTIVITIES

## Module One

# People Are People

## MODULE OUTLINE

**I. LABELS AND PEOPLE FIRST LANGUAGE . . . . . . . . . . . . . . . . . . . . . 3**

- A. PREJUDICE AND MISCONCEPTIONS . . . . . . . . . . . . . . . . . . . . . 3
- B. GRAMMATICALLY INCORRECT . . . . . . . . . . . . . . . . . . . . . . . . 5

**II. FUNCTIONAL DEFINITION OF DEVELOPMENTAL DISABILITY . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 8**

- A. EVOLUTION OF TERM . . . . . . . . . . . . . . . . . . . . . . . . . . . . 8
- B. CHARACTERISTICS . . . . . . . . . . . . . . . . . . . . . . . . . . . . 10
- C. FUNCTIONAL DEFINITION . . . . . . . . . . . . . . . . . . . . . . . . . 12

**III. DISCRIPTIONS OF COMMON CONDITIONS LEADING TO DEVELOPMENTAL DISABILITIES . . . . . . . . . . . . . . . . . . . . . . . . . 16**

- A. MENTAL RETARDATION . . . . . . . . . . . . . . . . . . . . . . . . . . 16
- B. EPILEPSY . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 22
- C. CEREBRAL PALSY . . . . . . . . . . . . . . . . . . . . . . . . . . . . 24
- D. AUTISM . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 25
- E. OTHER CONDITIONS . . . . . . . . . . . . . . . . . . . . . . . . . . . 26

**IV. STATISTICS . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 30**

- A. NUMBERS SERVED . . . . . . . . . . . . . . . . . . . . . . . . . . . . 30

# PEOPLE ARE PEOPLE

Module 1 - Foundation Training

## INTRODUCTION TO TRAINING

Introduction to Training

Alphabetizing / Airplane Toss Activity

### ACTIVITY *"Alphabetizing"*

***Activity Objective:** The purpose of the activity is to introduce participants to each other and to promote social interaction within the group. It will also introduce the concept of labeling.*

***Methods:***

- ***Handout blank name cards and tell the participants to hold onto them for a minute.***
- ***Tell the participants that they are now going to alphabetize themselves. They are to arrange themselves alphabetically by the first letter of their last name. Give them five minutes or so to do this. Once they are in alphabetical order tell them to write their name on their name card. They are then to give enough information about themselves to the neighbor on their right so that he/she can introduce them to the class in a round robin fashion.***
- ***The trainer should first introduce him or herself, telling a bit of personal background, how they got into training, and any other information the participants may enjoy hearing. Then allow participants to introduce each other. Everyone will be looking at the name cards to see if they indeed managed to get into alphabetical order. This will also generate group interaction. Allow partners to introduce each other to the class.***

***NOTE:** You will notice that people begin to label themselves as "A's," "All T's over here," "S's are better than F's," etc. Use this behavior as an introduction to labeling and using People First language. This is a great example of how easy it is to label individuals and to develop social distinctions and prejudices.*

- ***Take care of general information (where's the bathroom, where food services, if any, are located, etc.) and any administrative details that need attention.***

**Optional Activity: Airplane Toss**

- Introduce this exercise by telling the participants that they are now going to engage in an activity that will allow them to use not only their powers of observation but their social skills as well.
- Describe the activity and tell them that they will introduce the person whose airplane they retrieve.
- Let the participants know that they will have about ten minutes to find the person they are looking for and to learn enough about them to use as an introduction.
- This exercise will result in a lot of interaction and mingling among participants.

**Methods:**

- Have participants write three descriptions of themselves (i.e., color of their hair, what they are wearing, etc.) upon a piece of 8 1/2" X 11" notebook paper.
- Tell them to fold the notebook paper into an airplane and "sail" it across the room.
- Each participant should pick up someone else's airplane and find the individual described on it.
- They should spend a couple of minutes learning about that individual (i.e., what position he or she will be holding, favorite activities, future goals, etc.).
  The most important question they should ask and then write down is: Why do you want to work in your selected position?
  Note: If there is an unequal number of participants, the instructor should make arrangements for someone to introduce two people, or the instructor should introduce a participant to even the responses.
- Starting at a point in the room, have participants introduce the people whose airplane they have retrieved.
- Summarize the exercise by going over the reasons why people have selected to work in their respective areas and making the statement that "We are all in training for the same purpose; to learn the values and attitudes that influence the State of Oklahoma as it delivers services to people with developmental disabilities".

**Important Note:** Make the point that all people are "people." They will hear this statement many times throughout the training.

- At this point, it would be helpful to give the participants information on such things as where the restrooms are located, food services available (if any), break and session lengths, etc.

- After the exercise has concluded, you may begin presenting Module One information with the following introduction:

## INTRODUCTION

INTRODUCTION

**PRESENT** Over the next few hours we will discuss the term "developmental disability" in detail. We will look at how language and labeling affect people. We will also look at some misconceptions that have been held in the past and are often still believed today. We will discuss changes that have occurred throughout history as well as some trends for the future.

***Objective 1:***
***Define and be able to use People First language. Discuss how the application of labels affect the lives of individuals with developmental disabilities.***

*Objective One*

# LABELS AND PEOPLE FIRST LANGUAGE

LABELS AND PEOPLE FIRST LANGUAGE

As recently as 1975, a leading medical guide labeled individuals with mental retardation as *morons, imbeciles, and idiots* -- words out of the dark ages. We are also familiar with the terms "mongoloid," "retardate," "vegetable," "quadriplegic," "epileptic," etc.

PREJUDICES

***People are... PEOPLE!***

As a society we are becoming aware of how dehumanizing labels are. We know that all

Dehumanizing

human beings are people and deserve our respect not because of who they are, or what they are, or how much they earn, but just because they *are* people.

**Labels can result in prejudice and misconceptions.** Labels can lead to individuals being shunned by society or even worse, as history shows, being tormented or neglected.

***LABEL JARS, NOT PEOPLE!***

First words

We know from research and personal experience that **the first words we hear describe a person are the words we remember most clearly.** The first words out of our mouths call attention to and focus on specific aspects of an individual. For example, if we hear the terms "retarded child," or "epileptic woman," or "autistic man," the words imprinted on our minds are *retarded, epileptic,* or *autistic*. People tend to remember the disability, not the person, the citizen, or the child.

***Ask the group for examples of People First language. Also list terms that aren't People First and point out differences.***

Throughout this training, you will notice that the trainer is using terms such as:

"A child with mental retardation."
"A woman with cerebral palsy."
"People with developmental disabilities."
"A citizen who has a disability."

People First Language

This is called **People First** language. Progressive workers in this field use People First language.

**We request that you also use People First language.**

> **People are more than their disability.**

People are more than their disability. They smile, they laugh, they are proud of the quality of their work. They are somebody's husband, wife, brother, sister, son, or daughter. They are artists, musicians, athletes; just like the rest of us. **Therefore, we use language that, if it has to refer to a disability at all, it does so in a respectful manner.** We do not use terms such as:

"The handicapped..."
"The MR's or the CP's..."
"The epileptic..."

Imply homogeneity

**These terms imply homogeneity**; that all people who may have one characteristic in common are somehow alike in all other respects. When we lump people together, we take away their individuality.

GRAMMATICALLY INCORRECT

**And, not only are these terms disrespectful, they are also grammatically incorrect.** An adjective such as the word "handicapped" is used to describe a noun such as "child." An acronym (letters that stand for something) may be acceptable to describe a business such as IBM, but is inappropriate when describing a human being.

The use of verbs is also important. If the verb "is" is used when describing a person, it defines the entire person.
*Example: "The person is disabled."*

- If the verb "has" is used in a sentence to describe an individual, it only describes one aspect of that person.
  *Example: "The person has cerebral palsy."*

Some other suggestions for writing and speaking about developmental disabilities are included in the handouts and exercises that follow.

## HANDOUT

***Handouts 1A, 1B, 1C, and 1D (People First Language).***

***Read Handout 1A, "You and I," to the class. Conduct a discussion on People First language:***

- ***Make the point that "We don't say that a person with arthritis is an arthritis person or that a person who has had a heart attack is a heart attack person."***
- ***You may want to make a game out of the group catching you and each other in the use of non-People First language using small prizes or "points" as rewards. You may even want to intentionally make mistakes – people love to catch authority figures in error.***

Handouts 1A, 1B, 1C, 1D (People First Language)

## SHOW

***Transparencies 1.1, 1.2 (John is...)***

- ***After Transparency 1.1, ask the class how they would feel if it was their first night to work and the supervisor told them that they would be working with this person (John). What preconceived opinion would they form?***
- ***Show Transparency 1.2. Ask the class if it sounds as if the person that wrote these things really knew John? Does it give you some ideas of ways to effectively interact with John?***

Transparencies 1.1, 1.2 (John Is...)

## EXERCISE

***"Using People First Language"***

Exercise: People First Language

***Have the participants complete the Language Exercise in class. When everyone is finished, read through the exercise and lead a discussion on the most appropriate answers to the phrases.***

---

## INSTRUCTOR QUESTIONS

1. **What is People First language? Give an example.**

2. **The ______________ words out of our mouths are the words people ____________________.**

3. **How can the use of language that isn't People First language promote the labeling of individuals with developmental disabilities?**

☞ **Emphasize that the concept of *People Are People* drives our training. This is the concept that all people working with individuals with developmental disabilities should adopt.**

---

***Objective Two:***
***Identify the criteria involved and write a functional definition of the term "developmental disability."***

**Objective Two**

# HOW THE TERM "DEVELOPMENTAL DISABILITY" CAME INTO EXISTENCE

CREATION OF THE TERM "DEVELOPMENTAL DISABILITY"

**DISCUSS** ***Be sure to emphasize the following points:***

- ***How "categories" of disabilities were funded based on the number or strength of their lobbying efforts.***
- ***Why rare conditions received fewer funds.***
- ***Why legislators felt that all individuals with disabilities were served when they voted on a specific program for disabilities.***

# EVOLUTION OF DEFINITION

EVOLUTION OF TERM

**PRESENT** What is a "developmental disability?" Where did the term come from?

Funding

Before 1984, children and adults with mental retardation, epilepsy, autism, cerebral palsy, or other disabilities were eligible for governmental funding on a *categorized* basis. In other words, if a disability affected a large number of people, e.g. mental retardation, and had vocal advocates who lobbied for services and programs, it received program funding. However, if a disability was a rare condition that only affected a relatively small number of people, such as spina bifida, only a small number of family or friends could lobby, even though the need for help was just as great as more prevalent conditions. The concern grew that small groups were not receiving enough services, even though their needs were just as great.

Needs Met

Also, legislators, policymakers, and the general public -- who were not specialists in the field of disabilities -- **often thought everyone's needs were being met when they voted for a program designated "disability"** because they had little education on what constituted the various programs.

Subsequently, in order to bring about fairness in distribution of government funding and reduce confusion, four groups (mental retardation, autism, epilepsy, and cerebral palsy) came together and the term "developmental disability" was created. The definition was later expanded to include other groups beyond the original four based on functional abilities.

Exercise:
"Definition"

## EXERCISE *Definition Exercise*

***Objective: To allow participants to shape their individual definitions of the term "developmental disability" and to compare these to the definition currently in use by the State of Oklahoma.***

***Introduce the following section by asking the participants to write down their own definition of the term "developmental disability." Give them a couple of minutes to do so then ask them to share with the group. List these definitions on a flip chart. After you have come to a general agreement as to what they believe constitutes a developmental disability, present the following information on developmental disabilities and tie it into the definitions the group has already arrived at. Be sure to clarify what is meant by the term "functional definition."***

# CHARACTERISTICS

CHARACTERISTICS

**SHOW** ***Transparency 1.3 (A Developmental Disability Is...)***

Transparency 1.3 (Characteristics)

The following were the characteristics agreed upon by the groups involved.

**A Developmental Disability is a:**

* Mental and/or physical impairment, which;
* Starts before age 22;
* Continues indefinitely or for an extended period of time;
* Results in a functional limitation in three or more areas (described below);
* Person needs an individually planned or coordinated combination or sequence of services.

A Developmental Disability Is...

**Five prerequisites must be met before a condition is described as a developmental disability.** First, the disability **must be the result of either a physical or mental impairment** or both. Second, it **must have occurred before the age of 22.** Third, it must be **chronic**, meaning that it is likely to last either for the lifespan of that individual or for a very long time. Fourth, the disability **must result in significant functional limitations in three or more of the following areas of life**, and fifth, there is **a need for support**.

Prerequisites

**SHOW** ***Transparency 1.4 (Seven Major Life Areas) Point out each characteristic separately and ask the group to give examples, i.e., examples of self-care, learning, mobility, etc.***

Transparency 1.4 (Seven Major Life Areas)

## SEVEN MAJOR LIFE AREAS

✓ Self-care activities are the things people do daily to meet their basic life needs. They include eating, personal hygiene and grooming.

✓ Receptive and expressive language are the verbal and nonverbal skills a person needs to understand others and to express his/her ideas and feelings.

✓ Learning is the ability to acquire new behaviors, perceptions and information; the ability to apply past experiences to new situations.

✓ Mobility is the ability to move from one place to another with or without mechanical aids.

✓ Self-direction is the ability to take care of oneself; the person is able to make sound personal decisions and protect his/her self-interests.

✓ Capacity for independent living describes a person's ability to live without extraordinary support in a way that is age-appropriate.

✓ Economic self-sufficiency describes a person's capacity to maintain adequate employment and financial support.

Seven major life areas

**PRESENT** The term "developmental disability" does not describe a person. It is not a disease. It is not even one type of condition a person may have. A developmental disability is just that --- a term that includes disabilities which occur in the developmental years (before the age of 22). It may be caused by a physical or mental impairment or a combination of both. It is an umbrella term that includes a large number of disabilities, all of which have the common feature of occurring during the developmental years of life. Developmental disabilities cannot be cured -- they are long-term and chronic. The impact of the disability on an individual's life may be lessened however with the appropriate care and support.

Umbrella term

## FUNCTIONAL DEFINITION

FUNCTIONAL DEFINITION

The term is also a **functional definition** -- it focuses on how a disability interferes with a person's abilities and capacity to perform major life activities discussed earlier.

**SHOW** ***Transparency 1.5 (Functional Definition)***

***Discuss in depth at this point the concept of functional definitions and how these differ from academic definitions.***

Transparency 1.5
(A Functional
Definition)

> **A functional definition** focuses on how a disability interferes with a person's abilities and capacity to perform major life activities.

**PRESENT** The term is also used as an *eligibility* definition; that is, it is sometimes used to define who may or may not be eligible for limited public or private resources. It intentionally limits the number of people who can access those resources. It should be noted, however, that many programs in Oklahoma and other states are still categorical; that is, they may serve only one or two disability groups and do not use the federal developmental disabilities definition for eligibility or entitlement determination.

Eligibility Definition

Mental retardation, epilepsy, autism, muscular dystrophy, spina bifida, and cystic fibrosis are examples of some conditions that fall under the term "developmental disability." It is important to remember that there are many causes of a disability. In fact, there are around 300 possible causes of mental retardation alone.

**The disabilities discussed in this training are some of the most common forms but are by no means the only types.**

You may have friends or relatives that have disabilities that are not developmental disabilities. Their disabilities, however, may be just as severe. In other words, they may require assistance with eating, dressing, work, etc. For example, strokes, car accidents, war-related injuries, would not ordinarily be developmental disabilities since they almost always occur in adulthood. However, people who have these conditions require many of the same services as people with developmental disabilities.

Disabilities That Do Not Qualify

***Ask the group if they can think of examples of disabilities that would not be classified as a developmental disability. Discuss why they would or would not be.***

Finally, the individual with developmental disabilities has need for special, interdisciplinary and/or generic care, treatment, or other services that are individually planned and coordinated by service providers.

Provide Only What Is Needed

**Not everyone wants or needs our services, even though they may be eligible.** We try to provide only what is needed and desired by the consumer, **no more and no less**. To do otherwise would be to intrude into the lives of our fellow citizens. Many individuals (for example, adults with mild mental retardation ) come into our system only in times of crises (e.g., death in the family, divorce, loss of job). They do not want or need us at other times. In fact, they prefer to avoid the stigma associated with our specialized services. Many families have the resources necessary to meet their needs. Perhaps the only service they require is information, which could be provided through something as simple as a telephone call or attendance at a training session like this one.

Not Synonymous

**People with physical disabilities do not necessarily have mental disabilities.** For example, a person with cerebral palsy may have a developmental disability because of extensive physical disabilities and yet be extremely intelligent. A person with a learning disability may not fall into the developmental disabilities category since he or she is not severely limited in three out of the seven life areas. Others may not qualify because their disabilities occurred after the age of 22 (example: head injuries as an adult).

**People with physical disabilities do not necessarily have mental disabilities**

# SUMMARY

SUMMARY

***In the section summary, be sure to point out:***

- ***When a developmental disability occurs;***
- ***What can contribute to the occurrence of a developmental disability;***
- ***If a developmental disability can be cured;***
- ***The life areas in which an individual's ability to function may be limited;***
- ***What types of disabilities may not qualify for services under the functional definition used by the State of Oklahoma. Why?***

To summarize, developmental disabilities occur during the formative years of life **from before birth up to the age of 22**. Often there is no known cause for a specific disablity. Conditions such as physical and neurological impairments, premature birth, maternal drug and/or alcohol abuse, poor nutrition, and poverty may contribute to developmental disabilities. The one common factor of these disabilities is that they **occur in the developmental years of life** and limit an individual's ability to function in **at least three of the major life areas** as described in the federal definition.

One Common Factor

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INSTRUCTOR QUESTIONS

4. **Why was there a need (especially concerning funding of programs) for a better definition of what constituted a developmental disability?**

5. **Why did rare conditions receive smaller funding amounts?**

6. **What is meant by the term "functional definition?"**

**7. List three or more disabilities that are not developmental disabilities.**

**8. Is a developmental disability a disease? Why or why not?**

**9. Can developmental disabilities be "cured?" Are these disabilities permanent?**

---

***Objective 3:***

***Describe common conditions leading to developmental disabilities and write a brief description of each.***

***Objective Three***

**PRESENT** Definitions of disabilities **may** be helpful in understanding the level of an individual's need. It is important to remember that the people with disabilities are the ultimate resources and the ultimate advocates in defining what they need.

# DISCRIPTIONS OF DISABILITIES

**EXAMPLES OF DISABILITIES**

***If wished, you may break the large group into five smaller groups and allow them each to present one of the sections on the specific disabilities: i.e., Mental Retardation, Epilepsy, Cerebral Palsy, Autism, and Other Conditions that they have in their participant's manual. (Additional information is included for the trainer's benefit.)***

## MENTAL RETARDATION

**MENTAL RETARDATION**

Most people served by the State of Oklahoma have mental retardation. They may also have more than one disabling condition (such as cerebral palsy or epilepsy). **Developmental disabilities and mental retardation are not the same. People**

**with mental retardation may have a developmental disability but not all people with developmental disabilities have mental retardation.**

**People with mental retardation have developmental disabilities but not all people with developmental disabilities have mental retardation.**

**SHOW**

***Transparency 1.6 (Definition)***
***Handout 1E (Facts)***

***Discuss what needs to exist for a person to be classified with mental retardation. Be sure to point out that this is a new definition adopted by the American Association on Mental Retardation.***

Transparency 1.6 (Mental Retardation)

Handout 1E (Facts)

**Mental Retardation** refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas; communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests itself before age 18.

In other words, the most recent definition states that mental retardation refers to substantial limitations in present functioning. The four key elements are:

Key Elements

- Capabilities
- Environments
- Functioning
- Need for Supports

***Discuss with participants situations where a person might meet one or two of the requirements but still not be labeled mentally retarded.***

## Causes of Mental Retardation

Causes

**SHOW** ***Transparency 1.7 (Causes)***

Transparency 1.7 (Causes)

Mental retardation may stem from literally hundreds of possible causes. Some of these are:

- Genetic/chromosomal or inherited traits (Down Syndrome);
- Infections (encephalitis or meningitis), and metabolic problems (diabetes or hyperthyroidism);
- Environmental influences during pregnancy;
  1. lack of oxygen to the brain at birth,
  2. chemicals and drugs (including alcohol) ingested during pregnancy,
  3. exposure to radiation,
  4. high temperature of a mother during early pregnancy.
- Other environmental factors (inadequate stimulation and love, or abuse, neglect, or other trauma during early childhood).

Prenatal causes

**Prenatal and Genetic Causes** (before birth) may result from chromosomal abnormalities in which parts of a chromosome that contributes information to the developing fetus are either defective or missing. Metabolic irregularities such as PKU where enzymes responsible for breaking down natural poisons in the body are missing can result in progressive damage to the brain. This condition can be corrected or minimized if detected early enough.

Structural problems where parts of the brain are missing or fail to develop properly can also lead to mental retardation.

**SHOW** ***Transparency 1.8 (Prenatal and Perinatal Causes)***

Transparency 1.8 (Prenatal and Perinatal Causes)

Perinatal causes

**Perinatal causes** (difficulties during birth) can result in mental retardation. Premature birth, trauma during birth or anoxia (a lack of oxygen to the brain) can result in damage to the brain and can result in mental retardation.

**SHOW** ***Transparency 1.9 (Postnatal Causes)***

Transparency 1.9 (Postnatal causes)

Postnatal causes

**Postnatal causes** (after birth) such as the following can lead to mental retardation:

- Trauma - automobile accidents and child abuse are common causes of trauma
- Poisons - lead and carbon monoxide poisoning can result in mental retardation in children
- Infections - infections such as meningitis or encephalitis can inflame the brain or result in high fevers that can lead to mental retardation
- Parasites - not seen so much in this country, but in other countries, parasites can cause cysts or inflammation of the brain

Degenerative diseases such as muscular dystrophy can lead to the lessening of physical or mental abilities. These factors, along with others, can lead to mental retardation in a developing individual. Some are preventable through good prenatal care and some may be lessened by good care and education. One thing to remember is that 75-80 percent of the time, no cause for the disability is found.

**We only serve a small number of all people labeled as mentally retarded. Most live, work, and play with the rest of us in society and only need help occasionally from the rest of us.**

## Support Required

Support Required

**The vast majority of people (90 percent or more) have only mild limitations and may require either limited or no additional assistance.** People with mild levels of mental retardation often have no known cause for their mental retardation. Social, family, and environmental conditions such as poverty, poor nutrition, maternal alcohol or drug abuse, premature birth, or early childhood abuse and neglect may contribute to this level of mental retardation. People with mild to moderate levels of mental retardation often need minimal support and have few or no additional handicapping conditions, such as epilepsy, physical disabilities, etc.

Minimal support

People with more severe mental retardation may have additional handicapping conditions and are likely to need support in various areas of their life. Physical disabilities, epilepsy, and hearing and visual impairments are often seen in this group of people.

More intensive supports

**We do not classify infants or children as developmentally disabled until they are older.** Labels are not helpful in early childhood. They may in fact lead to low expectations and reduced levels of support. They are often inaccurate, and even when correct, they do nothing to change the kind of stimulation and nurturing a child needs to grow and develop.

Labeling and support of children

# SUMMARY

SUMMARY

**It is very important to remember that most children and adults with mental retardation are not in our service system. Either they function relatively independently on their own, or their families provide the support necessary to meet their needs.**

Intermittant Use Of Services

The second thing to remember is that many people will use our services intermittently. Regardless of the severity of their disability, they may have enough support available to them from their family, friends, and community that they will only need our help during times of personal crises.

There are, however, people who need a great deal of support; socially, educationally, vocationally, and in terms of health care. Moreover, their families cannot provide such support.

These are the people who make up the majority of the people we serve.

**It is very important to remember that most children and adults with mental retardation are not in our service system. Either they function relatively independently on their own, or their families provide the support necessary to meet their needs.**

Making lives better

**You will note that in this training we are not focusing on why the developmental disability occurred but in how we can make people's lives better.** We may not be able to cure their disabilities, but we can help them to maximize their potential.

Individuals with the same conditions may have different abilities. Although there may be similarities that help us in working with these individual's needs, we must always be aware that all people have different qualities which will shape their needs.

# EPILEPSY

EPILEPSY

**SHOW** *Transparency 1.10 (Epilepsy)*

Transparency 1.10 (Epilepsy)

Key Elements

**PRESENT** **Epilepsy is a chronic brain disorder characterized by seizures.** These seizures can be described as uncontrolled body movements, unusual sensations (such as something crawling on the skin), altered perceptions (such as an awful smell), or various mixtures of movements and sensations that interfere with a person's normal function and behavior.

Percentages

**Seizures occur in approximately one to two percent of the general population but as with mental retardation, only a very small number of people with epilepsy have conditions so severe as to be classified as developmentally disabled.** Also, as noted earlier, people with one disability can have other disabilities as well. Thus, the percentages of people with a disability may be a duplicative number. Seizures can occur in many forms from severe body convulsions and unconsciousness to less intensive psychomotor epilepsy. An individual with psychomotor epilepsy may continue normal activities but exhibit amnesia or loss of awareness. The individual may not even be aware that s/he has experienced a seizure.

Predisposition

**Although the disease itself is not inherited**, recent research suggests that, in some cases, the predisposition to the disease may be a hereditary trait.

**People with epilepsy usually are only troubled by mild seizures that may be controlled with medication.** They enjoy all aspects of society with little interference from their disability.

Medication

## SHOW

***Video "Epilepsy: A Positive I.D."***

Video: "Epilepsy: A Positive I.D."

***While this video is an excellent, contemporary viewpoint of epilepsy (especially the use of People First language, be aware that some subtle distinctions need to be pointed out:***

- ***Indirect negative value is placed on mental retardation by the producers stressing that people with epilepsy are not mentally retarded (although they concede that some people with epilepsy also have mental retardation.***
- ***Be sure to emphasize under what circumstances an ambulance might be called with Generalized Tonic Clonic epilepsy.***
- ***Call attention to the inappropriateness of placing objects in people's mouths or restraining them.***

***Also Discuss:***

- ***How you can tell if an individual is having a seizure.***
- ***What should you do if an individual is having a seizure.***

## SUMMARY

**SUMMARY**

Epilepsy can be controlled by medication in a large percentage of individuals. People with epilepsy may be restricted by a physician from certain activities such as driving, swimming or working on a ladder. With medication and supervision, protective and/or adaptive equipment, as well as support from others, people with even severe epilepsy can participate in most activities.

# CEREBRAL PALSY

CEREBRAL PALSY
Transparency 1.11 (Cerebral Palsy)

## SHOW

***Transparency 1.11 (Cerebral Palsy)***

Key Elements

Cerebral palsy describes physical disabilities resulting from physical damage to the brain which, in turn, affects muscle coordination. This difficulty may be so mild that it involves only fine motor skills, such as writing or sewing, or it may be so severe that all motor activity is difficult and activities such as walking, talking and taking care of personal needs are hindered.

Causes

**These motor activities usually result from damage to the brain either before, during, or after birth** and can arise from a variety of reasons including inherited metabolic conditions and diseases such as Rubella or toxemia during pregnancy. Oxygen deficiency and trauma during delivery can also result in cerebral palsy. Evidence of brain damage may not show up until several months after birth and, in some cases, may not be recognized for several years.

**Cerebral palsy is not progressive**

Technological Aids

Cerebral palsy is not progressive (it does not get worse). It is not contagious. It cannot be cured. However, as will be seen in the section on technology, there are wonderful new technological developments -- wheelchairs which can be activated by blowing air through a tube, "talking" communication boards, electronic methods of muscle movement -- that allow the individual with cerebral palsy to live a full life. In addition, physical therapy, speech therapy, and in some cases orthopaedic surgery allow an individual to compensate for the disability.

## SUMMARY

SUMMARY

As the child with cerebral palsy grows, he or she may require services such as in-home support services, continuing therapy, vocational training, adapted environments or equipment, living accommodations, transportation, recreation/leisure programs and employment opportunities. Above all, however, people with cerebral palsy need, as do all of us, the opportunity to live as normally as possible in our society.

## AUTISM

AUTISM

Transparency
1.12 (Autism)

**SHOW** ***Transparence 1.13 (Autism)***

Key Elements

Autism is usually present at birth but often not diagnosed before the age of three. It results in the child being unable to communicate effectively or to process information from his or her environment. Children with autism may appear withdrawn and unresponsive, although in some cases such children may also possess exceptional ability in areas such as music or mathematics.

Autism is characterized as a disturbance in the following areas:

- speech and language
- rate of development
- ability to relate to people and things
- perception
- use of mannerisms

Perception difficulties

Individuals with autism may have difficulty in perceiving the world around them as other people perceive it. They may also has difficulty in communicating their perceptions to other individuals. These characteristics usually begin before the age of three and may range from mild to severe. "Autistic-like" behavior is a term often used to describe the repetitive behaviors and lack of awareness of their environment that people with autism may display.

> **It is a sad commentary that parents, especially mothers, have had a long history of being unfairly blamed by professionals for their child's disability.**

Causes

Parenting

**The cause or causes of autism are still under investigation at this time but we do know that autism is not caused by specific types of parenting as was once suggested.** It is a sad commentary that parents, especially mothers, have had a long history of being unfairly blamed by professionals for their child's disability.

## SUMMARY

**SUMMARY**

People with autism have a difficult time dealing with their environment; they may desire familiar things and set routines. Changes in routine can be very disturbing. Maturation may be slowed and there may be a lack of physical, social and learning skill development. People with autism can benefit from structured programs that stress social and language skills as well as adaptive methods for dealing with their environments.

# OTHER CONDITIONS

OTHER CONDITIONS

Although the conditions just discussed -- mental retardation, epilepsy, cerebral palsy and autism -- make up the largest numbers of people with developmental disabilities, other conditions can produce disabilities also. Muscular dystrophy, spina bifida, cystic fibrosis, hearing impairment, and vision impairment are among disabilities that can interfere with an individual's physical development and ability to learn. If these are sufficiently severe to result in substantial functional limitations in three of the major life areas, they can be classified as developmental disabilities as previously defined.

## ENVIRONMENTS WHICH DISABLE

ENVIRONMENTS WHICH DISABLE

Just as the bones and muscles of children and adults with cerebral palsy can be permanently damaged through lack of stimulation and proper positioning, there are behaviors and physical disabilities that can occur in other people with developmental disabilities because of the environment in which they live.

For example, self-injurious behavior, aggressiveness, learned helplessness, inappropriate noise making, are all behaviors that can be developed in a setting where human beings are not given love and nurturing, are surrounded by inappropriate role models, or are not given adequate physical care. Also, misuse of psychotropic drugs, inadequate physical therapy, and the frustration that develops from being unable to communicate can cause additional behavioral as well as physical disabilities.

Power of the Environment

## POWER OF THE ENVIRONMENT

While it is true that the problems described above have historically occurred in large congregate settings, there is evidence that those same problems can and do occur in the newly emerging community programs when staff are not aware of the power of the environment on human beings.

Unfortunately, even in small, dispersed homes and workplaces in the community, these same problems can also develop.

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INSTRUCTOR QUESTIONS

**10. Explain what is meant by each of these elements when defining mental retardation.**
  - **Capabilities**
  - **Environments**
  - **Functioning**

**11. What may be some of the causes of mental retardation? Are we always aware of the causes?**

**12. Define: Prenatal**
**Perinatal**

**13. List two prenatal and two perinatal causes of mental retardation.**

**14. Is mental retardation a part of all developmental disabilities? Why or why not?**

**15. Of the percentage of individuals with epilepsy, how many can control their seizures with medication?**

**16. Is it possible that an individual not be aware that he or she is experiencing a seizure? What should you do in this situation?**

**17. The condition of cerebral palsy results from physical damage to what part of the body?**

**18. What types of support can help an individual with cerebral palsy compensate for his or her condition?**

19. A disturbance in what areas is classified as autism?

20. What type of activities may be disturbing to an individual with autism and why? Why are structured environments important?

21. The lack of what two things can permanently damage the bones of adults and children who have cerebral palsy?

22. How can the environment in which someone lives contribute to patterning inappropriate behaviors?

**SECTION SUMMARY:**

1. Discuss the differences between:
    - Mental Retardation
    - Epilepsy
    - Cerebral Palsy
    - Autism

---

***Objective 4:***
***List three statistics concerning people with developmental disabilities.***

**Objective Four**

# STATISTICS

**STATISTICS**

## HOW MANY PEOPLE HAVE DEVELOPMENTAL DISABILITIES?

NUMBERS SERVED

It is important to remember that **less than three percent of all Oklahomans have what has been defined as a developmental disability.** Of those, almost 50,000 individuals and their families are among some of the state's most vulnerable, overlooked and under-estimated citizens. No comprehensive needs assessment of these individuals and their families has been done. Most live in their own homes and receive no support of any kind from the state.

**It is important to remember that less than three percent of all Oklahomans have what has been defined as a developmental disability.**

Percentages

Approximately 7,500 persons are currently served by programs in which the department participates. Another 1,000 individuals and their families are on waiting lists maintained by the Department of Human Services. An

Numbers Served in Oklahoma

unknown number are on waiting lists maintained by service providers in communities throughout Oklahoma.

Transparency 1.13 (Statistics)

Handout: Oklahoma Statistics

## SHOW

***Transparency 1.13 (Statistics)***
***Handout 1.E (Oklahoma Statistics)***

***Explain that these are National statistics compiled on all disabilities, not only developmental disabilities. These are 1992 statistics, feel free to use more recent information if you have access to it.***

National Statistics

The National Organization on Disability compiled the following national statistics. (Please remember that this information is based on all disabilities, regardless of severity or age of onset.)

- 43 million Americans have some type of physical or mental disability (17 percent of total population).
- 22 million Americans are hearing impaired; 2 million are deaf.
- 2.5 million are severely visually impaired, while 120,000 are totally blind and 600,000 are legally blind.
- For all age groups, females report higher percentages of physical functional limitations than do males.
- 2 million people with disabilities live in institutions, including nursing homes, mental hospitals, residential facilities and mental retardation facilities. Over 1.3 million are in nursing homes.
- On average, people with disabilities have less education, less income, fewer job opportunities and fewer social contacts than others.
- 8.2 million working aged adults with disabilities were unemployed at the beginning of 1990. People with disabilities are the most welfare dependent minority in the U.S.

- More than 46 percent of all people over 65 have some type of disability.
- More than 25 million people with disabilities are registered voters.
- There are approximately 177,000 Americans with Spinal Cord Injury.

## INSTRUCTOR QUESTIONS

**23. What percentage of Oklahomans have any form of developmental disability?**

**24. Approximately what percent of individuals with developmental disabilities are currently served by programs in which the Developmental Disabilities Services Division (DDSD) participates?**

**25. What percentage of the total population of Americans have a physical or mental disability?**

**26. Why are people with developmental disabilities considered to be the most welfare dependent minority in the U.S.?**

# MODULE SUMMARY

**MODULE SUMMARY**

**SHOW** ***Video "A New Way of Thinking"***

***Discuss with the group:***

- ***What is meant by the term "A New Way of Thinking?"***
- ***Give some examples of things that are currently happening that are positive examples.***
- ***Is Oklahoma following the path described in the video? Why or why not?***

Video: "A New Way of Thinking"

# HANDOUTS

## Module One

# You and I

*By Elaine Popovich, Home Manager Lutheran Social Services, Midland, Michigan*

I am a resident. You reside.

I am admitted. You move in.

I am aggressive. You are assertive.

I have a behavior problem.

You are rude.

I am noncompliant. You don't like being told what to do. When I ask you out for dinner, it's an outing. When you ask someone out, it's a date.

I don't know how many people have read the progress notes people write about me. I don't even know what is in there. You didn't speak to your best friend for a month after she read your journal.

I made mistakes during my check writing program. Someday I might get a bank account. You forgot to record some withdrawals from your account. The bank called to remind you.

I celebrated my birthday yesterday with five other residents and two staff members. I hope my family sends a card. Your family threw you a surprise party. Your brother couldn't make it from out of state. It sounded wonderful.

My case manager sends a report every month to my guardian. It says everything I did wrong and some things I did right. You are still mad at your sister for calling your mom after you got that speeding ticket.

I am on a special diet because I am five pounds over my ideal body weight. Your doctor gave up telling you to lose weight. I am learning household skills. You hate housework. I am learning leisure skills. Your shirt says you are a "couch potato."

After I do my budget tonight, I might get to go to McDonald's — if I have enough money. You were glad the new French restaurant took your charge card.

My case manager, psychologist, R.N., occupational therapist, physical therapist, nutritionist, and house staff set goals for me for the next year. You haven't decided what you want out of life.

Someday I will be discharged...maybe. You will move onward and upward.

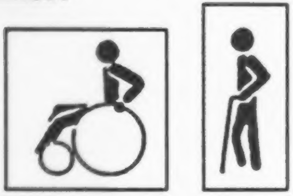
*(Reprinted with permission of The Cadre to Promote Normalization in Michigan from their newsletter, Framework.)*

*Department of Human Services*
*Developmental Disabilities Services Division*
*Community Relations Unit*
*P.O. Box 25352*
*Oklahoma City, OK 73125*

# It's the 'Person First" - Then the Disability

## What do you see first?

- *The wheelchair?*
- *The physical problem?*
- *The person?*



If you saw a person in a wheelchair unable to get up the stairs into a building, would you say "there is a handicapped person unable to find a ramp?" Or would you say "there is a person with a disability who is handicapped by an inaccessible building?"

What is the proper way to speak to or about someone who has a disability?

Consider how you would introduce someone — Jane Doe — who doesn't have a disability. You would give her name, where she lives, what she does, or what she is interested in — she like swimming, or eating Mexican food, or watching Robert Redford movies.

Why say it differently for a person with disabilities? Every person is made up of many characteristics — mental as well as physical — and few want to be identified only by their ability to play tennis or by their love for fried onions or by the mode that's on their face. Those are just parts of us.

In speaking or writing, remember that children or adults with disabilities are like everyone else — except they happen to have a disabled. Therefore, here are a few tips for improving your language related to disabilities and handicaps.

1. Speak of the person first, then the disability.
2. Emphasize abilities, not limitations.
3. Do not label people as part of a disabled group — don't say "the disabled;" say "people with disabilities.
4. Don't give excessive praise or attention to a person with a disability; don't patronize them.
5. Choice and independence are important; let the person do or speak for him\herself as much as possible; if addressing an adult, say "Bill" instead of "Billy."
6. A disabled is a functional limitation that interferes with a person's ability to walk, hear, talk, learn, etc.; use handicap to describe a situation or barrier imposed by society, then environment, or oneself.

| **Say...** | **Instead of...** |
|---|---|
| child with a disability | disabled or handicapped child |
| person with cerebral palsy | palsied, or C.P., or spastic |
| person who has... | afflicted, suffers from, victim |
| without speech, nonverbal | mute, or dumb |
| developmental delay | slow |
| emotional disorder, or mental illness | crazy or insane |
| person who is deaf or hard of hearing | deaf and dumb |
| uses a wheelchair | confined to a wheelchair |
| person with retardation | retarded |
| person with epilepsy | retarded epileptic |
| with Down Syndrome | mongoloid |
| has a learning disability | is learning disabled |
| nondisabled | normal, healthy |
| has a physical disability | crippled |
| congenital disability | birth defect |
| condition | disease (unless it is a disease) |
| seizures | fits |
| cleft lip | hare lip |
| mobility impaired | lame |
| medically involved, or has chronic illness | sickly |
| paralyzed | invalid or paralytic |
| has hemoplegia (paralysis of one side of the body) | hemiplegic |
| has quadriplegia (paralysis of both arms and legs) | quadriplegic |
| has paraplegia (loss of function in lower body only) | paraplegic |
| of short stature | dwarf or midget |

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# USING LANGUAGE APPROPRIATELY

1C

Over the past twenty years, Americans have become aware of how the language they use can express prejudice, and many racial, sexual, or religious labels are no longer heard. However, common language still contains many terms and expressions that are inaccurate or degrading labels for people who have disabilities.

Roughly up to 15% of the American population has disabilities. Over and over, people with disabilities say that the greatest barrier they face is not the disability itself, but instead the negative attitude and lack of acceptance of the rest of society.

Language reflects the existence of those attitudes in society. "Handicapism" shows up in speech just as racism and sexism once did. A first step toward changing attitudes is changing the way that we speak.

## FOCUS ON THE INDIVIDUAL

Labels are so powerful that any unique identity of a person can be erased when the label is applied. Don't let a person's disability become his label — put it aside and see the individual instead. Instead of saying "my retarded son" say "my son who has mental retardation." A small difference, but it makes the child more important than the disability.

## BE POSITIVE

Words like "pitiful" or "hopeless" convey negative feelings. A person who has cerebral palsy is not a "CP victim." Someone who has multiple sclerosis is not "stricken by MS." Think of the image that is created by these emotional words.

It is better to say "she uses a wheelchair" instead of "she is confined to a wheelchair," and "he walks with crutches" rather than "he is crippled." Not only is this more positive but more accurate. As Bob Peters wrote in the DISABILITY RAG, "A wheelchair does not confine...It allows its user to move around, to go to work, to travel, to play."

## BE ACCURATE

The American vocabulary still contains a number of terms used to describe disabilities that are just plain inaccurate. Many of them are also very negative and degrading. A few examples are:

Deaf and dumb or deaf mute — out of date terms that were once used to describe a person who is deaf and can not speak. Many people with hearing impairments can speak, although their speech may be hard to understand.

Spastic — describes a muscle with sudden, involuntary spasms. It does not describe a person.

Suffering — saying that someone suffers from a disability implies that he or she is in constant pain from the disability. This is not usually the case.

Retard, gimp, paralytic — these words are put-downs. A person has mental retardation, walks with a limp, or is paralyzed.

It is also misleading to say "the disabled," which implies a group of people who are all alike and have a kind of separate status. The phrase "people with disabilities" is more appropriate and allows the emphasis to remain on the individual.

Avoid giving the impression that a disease is present when talking about a disability. A disability may result from a disease, such as polio, but it is not a disease. Neither is the person with the disability unhealthy or contagious. People with disabilities should not be referred to as "patients" or "cases" unless they are under medical care.

Remember that a disability is a condition that interferes with a person's ability to do something independently — walk, see, hear, learn, lift, etc. Other abilities are still present! People with disabilities, no matter how severe their disabilities, have capacities, gifts, contributions to make, if only we will give society opportunities to get to know them as individuals. The words we use must convey this message.

Those of us who work and live with people who have disabilities need to provide models for these better ways of using language. Making others aware of the stereotypes in their language will help make them aware of the barriers that exist for people who have disabilities.

PEAK PARENT CENTER, INC., 1988

# TIPS ON WRITING ABOUT PEOPLE WITH DISABILITIES

**Think "people first."** Refer to the person first and the disability second. Never equate a person with a disability — by referring to someone as "an epileptic," for example.

**Avoid negative words** like "unfortunate" or "stricken," "crippled" or "deaf and dumb." On the other hand, avoid casting a person with a disability as a superhuman model of courage.

**A developmental disability** is not a disease. Do not use medical terms unless the person you're writing about has an illness as well as a disability.

**Do not confuse** mental retardation with mental illness. "Mental retardation" refers to significantly sub-average intellectual functioning. "Mental illness" refers to disturbances of mental and emotional equilibrium.

**Do not mention** a subject's disability unless it is relevant to the story. If you aren't sure how to refer to a person's condition, ask.

**Never refer** to a person as "confined to a wheelchair." Wheelchairs enable people to escape confinement. A person with a mobility impairment uses a wheelchair.

**Describe people without** disabilities as "typical" rather than "normal." People with disabilities are certainly atypical but not necessarily abnormal.

OKLAHOMA DEPARTMENT OF HUMAN SERVICES

# DEVELOPMENTAL DISABILITIES

A developmental disability is a severe, chronic disability of a person which:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- is manifested before the person reaches the age of 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self sufficiency;
- reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

It is difficult to pinpoint exactly how many Oklahomans have mental retardation because so many are able to function well and live in their own communities.

Simply stated, a person with mental retardation learns more slowly than others. According to the Association of Retarded Citizens/US, a person with mental retardation is "one who, from childhood, develops consistently at a below-average rate and experiences difficulty in learning, social adjustment and economic productivity."

The degree of mental retardation affects how much and how quickly a person who has mental retardation can learn. Mental retardation occurs once in every 33 people. Most are only mildly retarded.

Mental retardation is *not* mental illness. Mental retardation refers to a person's capability to think and reason. Mental illness is an emotional disturbance; there may be one occurrence or several which can develop at any time in a person's life. Like anyone else, a person with mental retardation may become emotionally disturbed or mentally ill.

## CAUSES

More than 200 causes of mental retardation have been discovered. Some experts estimate that as many as 1,000 causes remain to be identified. Mental retardation can be caused by environmental factors, genetic factors or a combination of both.

- **Environmental factors** include everything that goes on around a person. Those factors could include an infection during pregnancy, a lack of oxygen at birth, encephalitis, meningitis, lead poisoning, alcohol, drug abuse or poor parenting.
- **Genetic factors** are specific traits or characteristics a person inherits from both parents at conception. The condition that causes mental retardation can come from one parent or from both—depending on whether the characteristic is a dominant or recessive one.
- **Both genetic and environmental factors** can combine to cause mental retardation. Some pregnant women can take certain types of medication and have perfectly normal babies. Others may be allergic to or suffer severe side effects from the same medication and have a baby with mental retardation.

## CAN MENTAL RETARDATION BE CURED?

Some types of mental retardation can be prevented but there are no real cures yet—although researchers continue to search for one.

## EDUCATION, TRAINING AND THERAPY

While people with mental retardation learn more slowly than other people, they have many of the same hopes, fears, joys, problems and needs that others do. People who have mental retardation have talents and abilities that should be developed through individualized education, job training and physical, occupational, music, speech and recreational therapies.

The end result of education, training and therapy is a better, more normal life for people who have the same rights and responsibilities as anyone else. It is a life that should not be denied to people who have mental retardation.

## FOR MORE INFORMATION

Phone the area office hot lines nearest you:

| | |
|---|---|
| AREA I (Enid) | 1-800-522-1064 |
| AREA II (Tulsa) | 1-800-522-1075 |
| AREA III (Pauls Valley) | 1-800-522-1086 |

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# Oklahomans with Developmental Disabilities

Estimated number, by age group, of Oklahomans with Developmental Disabilities (Using Gollay and Associate and Department of Human Services Prevalence Rates)

| AGE | TOTAL OKLA. POP. | PERCENT of TOTAL | Gollay and Assoc. Est. (at 1.8% of pop.) | Okla. Dept. Hmn Svcs Est. (at 1.2% of pop.) |
|---|---|---|---|---|
| 0 - 17 | 837,007 | 27 | 15,066 | 10,044 |
| 18 - 44 | 1,282,949 | 41 | 23,093 | 15,395 |
| 45 - 64 | 601,416 | 19 | 10,825 | 7,217 |
| Over 64 | 424,213 | 13 | 7,635 | 5,090 |
| Total | 3,145,585 | 100 | 56,620 | 37,747 |
| Percent | 100 | | 1.8 | 1.2 |

Source: UAP of Oklahoma Database, 1992-93

Estimated Number of Oklahomans with Developmental Disabilities based on Race and Ethnicity (using Gollay and Associates and DHS Prevalence Estimates)

| Total Person Number | | G&A at 1.8% | DHS at 1.2% | Hispanic Origin Number | G&A at 1.8% | DHS at 1.2% |
|---|---|---|---|---|---|---|
| Total | 3,145,585 | 56,620 | 37,747 | 86,160 | 1,551 | 1,034 |
| Anglo | 2,583,512 | 46,503 | 31,002 | 35,924 | 647 | 431 |
| Black | 233,801 | 4,208 | 2,806 | 2,339 | 42 | 28 |
| American Ind., Esk, Aleut | 252,420 | 4,543 | 3,029 | 5,789 | 104 | 69 |
| Asian, Pac Isl. | 33,563 | 604 | 402 | 1,197 | 21 | 14 |
| Other | 42,289 | 761 | 507 | 40,911 | 736 | 491 |

Source: UAP of Oklahoma Database, 1992-93

Note: Information provided through the U.S. Department of Health and Human Services suggests that Black and Minority populations have higher prevalence of health problems than their non-minority same-age peers. Based on this data the DHS and G&A estimates may underrepresent the needs of people of color with regard to the actual prevalence of developmental disabilities in thesepopulations.

# OPTIONAL INFORMATION AND ACTIVITIES

## Module One

# SUPPLEMENTAL INFORMATION AND ACTIVITIES

## Module One

The Arc

Q&A

National organization on mental retardation

# Mental Illness in Persons With Mental Retardation

By Steven Reiss, Ph.D., Director, Nisonger Center UAP, Ohio State University; with comments from Benjamin Goldberg, M.D., University of Western Ontario, and Ruth Ryan, M.D., University of Colorado Health Sciences.

## What is mental health?

Mental health is a goal for all people, including those with mental retardation, not just those having difficulties. Mental health is an essential ingredient in the quality of life. The two main aspects of mental health are emotional well-being and rewarding social and interpersonal relationships. Emotional well-being is an important part of the gift of human life. Good social and interpersonal relationships are important for a rich and fulfilling life. People who have mental retardation are not in any way handicapped with regard to these human qualities — people with mental retardation are capable of a rewarding emotional life.

## What is mental illness?

Mental illnesses are severe disturbances of behavior, mood, thought processes and/or social and interpersonal relationships. There are many different types of mental illnesses that are seen in people with mental retardation. Some of the most common types are:

- **Personality Disorders**. These are long-term problems in adjustment. There a number of different subtypes. These individuals might be described by one or more of the following: emotionally needy, inappropriately seeking attention, nonassertive, always getting into fights or trouble, volatile, unstable, or having a problem with anger.

- **Affective Disorders**. These are disturbances in mood, usually indicated by profound sadness and noticeable changes in eating, sleeping and energy levels. Sometimes a disorder is indicated by sudden bursts of euphoria.

- **Anxiety Disorders**. These are indicated by the presence of excessive fears, frequent complaints of bodily ailments (headaches, stomachaches, dizziness), and excessive nervousness lasting for weeks. These include panic disorder, excessive fears, and post-traumatic stress disorder.

- **Psychotic Disorders**. These can be indicated by gross deterioration in behavior from previous levels, extreme disorientation and extreme confusion. Common signs are confusion (thoughts may jump from one idea to the next), hearing voices that are not there, excessive resentment and poor impulse control and behavior or habits that impress others as strange.

- **Avoidant Disorder**. The individual is a loner who avoids peers for fear of rejection, embarrassment or criticism. This condition is sometimes mistaken for autism.

- **Paranoid Personality Disorder**. The individual is very suspicious of others and quick to feel insulted and belittled. People with this problem may be volatile, stubborn, difficult to get along with, unreasonable, and have a tendency to overreact (make mountains out of molehills).

- **Severe Behavior Problem**. These include self-injurious behavior, hyperactivity, extreme irritability and chronic aggression or antisocial behavior. Researchers have found that behavior problems are sometimes related to depression, paranoia, psychosis, underlying medical conditions or specific brain dysfunction.

## What methods are used to diagnose mental illness in a person with mental retardation?

Mental illness should be diagnosed on Dimension II of the new American Association on Mental Retardation classification system (Luckasson et al, 1992). The diagnoses are best made by a qualified psychiatrist or clinical psychologist using the *Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association in 1988. Standardized assessment instruments include the Reiss Screen for Maladaptive Behavior, the Psychopathology Inventory, Abberant Behavior Checklist, and Behavior Problems Inventory. These instruments should be used only as one part of a general assessment and never as the sole or primary basis for diagnosis and planning treatment.

## Why do people with mental retardation develop mental illnesses and behavior problems?

Scientists still do not know for certain what causes most mental illness. Most researchers believe that both biological and psychological risk factors are involved, but to varying degrees depending on the specific disorder.

Some disorders may be wholly or largely caused by biochemical and structural abnormalities in the brain. Proclivities toward such abnormalities are sometimes inherited. Biochemical and structural abnormalities seem to be especially important in the occurrence of psychosis and explosive behavior. Life history and environment also may contribute to the development of the severity of psychosis and precipitate behavioral outbursts in susceptible individuals.

Some disorders may be wholly or largely caused by psychological factors, especially prolonged exposure to negative social conditions. The negative attitudes of the public toward people with mental retardation may promote the development of mental illnesses as a means of coping. For example, rebellion against negative social conditions can be labeled as "antisocial behavior;" the belief that a situation is hopeless often

# *People are... People!*

◆

***"We only serve a small number of all people labeled as mentally retarded. Most live, work and play with the rest of us in society and only need help occasionally from the rest of us."***

***It is very important to remember that most children and adults with mental retardation are not in our service system. Either they function relatively independently on their own or their family provides support necessary meet their needs.***

***It is a sad commentary that parents, especially mothers, have had a long history of being unfairly blamed by professionals for their child's disability.***

## 2

## MODULE TWO

# Foundation Level Training

## Changing Times

Department of Human Services
Developmental Disabilities
Services Division

# CHANGING TIMES

## Module Two

# OBJECTIVES

## Module Two

# CHANGING TIMES

Module 2 - Foundation Training

## LEARNING OBJECTIVES

***Primary Objective:*** Upon completion of this training and given the appropriate materials, the participant will be able to understand and apply the concepts of rights and values using the Principle of Normalization to people with developmental disabilities.

### *Secondary Objectives:*

- Compare and discuss periods of history in relation to the way individuals with developmental disabilities are viewed.
- Discuss the lessons we have learned from history regarding congregation and congregate settings.
- Compare and discuss the differences between legislative rights and other rights in relation to individuals with developmental disabilities.
- Identify types of abuse and neglect and discuss the term "non-aversive" methods.
- Discuss the things all individuals value and relate these values to people with developmental disabilities.
- Describe the Principle of Normalization; how it began and why it is called an ecological concept.
- List four misconceptions concerning the Principle of Normalization.
- Discuss the importance of using the principle of normalization to improve public imagery for people with developmental disabilities as well as promote full social integration within the community.
- Discuss three methods of recognizing and eliminating barriers to normalization.

# Training Information And Schedules

## Module Two

# Training Schedule

## *MODULE 2 - CHANGING TIMES*

| Objectives | Key Points | Exercises/ Activities | Transparencies | Handouts | Media | Length |
|---|---|---|---|---|---|---|
| 1. Compare and discuss periods of history in relation to the way individuals with developmental disabilities are viewed. | • Historical outline<br>• Perceptions<br>• Misconceptions<br>• The parent movement<br>• Affect on families | "Reasons" | 3.1 Historical Outline<br>3.2 Role Perceptions<br>3.3 Misconceptions<br>3.4 Closures<br>3.5 Populations Trends | 2A Wasting Away in Oklahoma<br>2B Sheltered Work<br>2C Hissom Client<br>2D Consent Decree | Video: "Willowbrook" (18min)<br>Video: "Rumania's Children" (22min) | 2hrs/30min |
| 2. Discuss the lessons we have learned from history regarding congregation and congregate settings. | • Why congregate settings do not work<br>• Segregation | "Rights" | 2.6 Congregation<br>2.7 Lack of Contact<br>2.8 Segregation | | | 45min |
| 3. Compare and discuss the differences between legislative rights and other rights in relation to individuals with developmental disabilities. | • Legislation<br>• Other rights<br>• Choice | "String Toss" | 2.9 Rehabilitation Act<br>2.10 IDEA<br>2.11 Developmental Disabilities...Act | | | 2hrs |
| 4. Identify types of abuse and neglect and discuss the term "non-aversive" methods. | • Mistreatment/ Maltreatment<br>• Abuse<br>• Neglect<br>• Exploitation<br>• Reporting Abuse<br>• Preventing Abuse<br>• Non-aversive Methods | "The Holiday Incident" | 2.12 Mistreatment<br>2.13 Physical Abuse<br>2.14 Sexual Abuse<br>2.15 Emotional Abuse<br>2.16 Exploitation<br>2.17 Neglect<br>2.18 General Rules | 2F Reporting Mistreatment | | 1hr/15min |
| 5. Discuss the things all individuals value and relate these values to people with disabilities. | | | 2.19 Values | | | 15min |
| 6. Describe the Principle of Normalization; how it began and why it is called and ecological concept. | • History<br>• Definition of Normalization | | | "The Enlightened Principle of Normalization" | | 30min |

| **Module Two - Training Schedule (cont.)** | | | | | | |
|---|---|---|---|---|---|---|
| 7. List four misconceptions concerning the Principle of Normalization. | • Misconceptions | | 2.20 Misconceptions | | | 15min |
| 8. Discuss the importance of using the Principle of Normalization to improve public imagery for people with developmental disabilities as well as promote full social integration within the community. | | | | | Cassette: "Donny At the Bus Stop" | 45min |
| 9. Discuss three methods of recognizing and eliminating barriers to Normalization. | • Clangers<br>• Appropriateness | | | | Video: "Clangers" | 45min |

# Changing Times

## MODULE OUTLINE

**I. HISTORY**

- A. HISTORICAL OUTLINE
- B. HISTORICAL ROLE PERCEPTIONS
  - 1. Subhuman Organism
  - 2. Object of Pity
  - 3. Object of Ridicule
  - 3. Unspeakable Objects of Dread
  - 4. Holy Innocents
  - 5. Eternal Child
  - 6. Sick Person
  - 7. Menace to Society
  - 8. Object of Charity
- C. MISCONCEPTIONS HISTORICALLY PERPETUATED
  - 1. Complete Dependency
  - 2. Mental Retardation Equals Mental Illness
  - 3. All Act Alike
  - 4. Ability Is Only As Good As IQ
  - 5. "Special" Environments
- D. PRESENT HISTORY
  - 1. The Parent Movement
    - a. The Association for Retarded Citizens (Arc)
    - b. Other parent groups
    - c. Help from policy makers
  - 2. Disillusionment
  - 3. The Oklahoma Experience
    - a. Disillusionment
    - b. Homeward Bound vs. THMC
    - c. Affect on Families

**II. LESSONS LEARNED FROM HISTORY**

- A. WHY CONGREGATION HAS NOT WORKED
  - 1. Subordinate Individualization
  - 2. Role Modeling
  - 3. Absence Promotes Segregation

    4. Skills Learned in Environments
    5. "Special" Environments
    6. Bigger Isn't Better
B. SEGREGATION
    1. Lack of Contact
    2. Environments

## III. RIGHTS

A. LEGISLATION
    1. Rehabilitation Act
    2. Individuals with Disabilities Education Act
    3. Developmental Disabilities Assistance and Bill of Rights Act
    4. Americans with Disabilities Act
B. OTHER RIGHTS
    1. Right to Vote
    2. Right to Have Grievances Heard
    3. Other Rights
C. CHOICE
    1. Rights
    2. Choices

## IV. MISTREATMENT/MALTREATMENT

A. PREVENTING MISTREATMENT/MALTREATMENT
    1. Abuse
        a. Physical abuse
        b. Sexual abuse
        c. Emotional abuse
    2. Exploitation
    3. Neglect
B. REPORTING MISTREATMENT
    1. Content of Reports
C. GENERAL RULES FOR PREVENTING MISTREATMENT
D. NON-AVERSIVE METHODS
    1. Code of Responsibility

## V. THE THINGS WE VALUE

A. PRACTICAL APPLICATIONS OF VALUES

1. The Principle of Normalization

## VI. NORMALIZATION

A. THE CONCEPT OF NORMALIZATION
    1. Characteristics
        a. Conditions of everyday living
        b. Normal rhythms of the day, week, year
        c. Normal activities
        d. Culturally appropriate teaching strategies
        e. Integrated lifestyles
    2. Wolfenburger's Contribution
    3. Ecological Concept
        a. People interact with the environment

## VII. MISCONCEPTIONS ABOUT NORMALIZATION

A. MISCONCEPTIONS
    1. Making People Normal
    2. No Support
    3. Applies Only to Mild Disabilities
    4. Scandinavian Concept
    5. Impractical and Idealized

## VIII. IMAGERY

A. BETTER IMAGES
B. INTERPERSONAL RELATIONS
C. FULL SOCIAL INTEGRATION
    1. Tips

## IX. RECOGNIZING AND ELIMINATING BARRIERS TO NORMALIZATION

A. AWARENESS OF CLANGERS
   1. Eye Clangers
   2. Ear Clangers
   3. Mind Clangers
B. APPROPRIATENESS

# LECTURE AND ACTIVITIES

## Module Two

# Changing Times

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# CHANGING TIMES

Module 2 - Foundation Training

"Those who don't benefit from history are doomed to repeat it."

Santayana

## PRESENT

INTRODUCTION

As Santayana so succinctly put it, if we do not learn from the mistakes made by generations past, then we will repeat those mistakes. We have seen examples throughout history of conditions that degraded and jeopardized individuals. Child labor in factories, orphanages, and slave trading are all situations from which we have learned and put behind us. Our treatment of individuals with developmental disabilities is also an example.

We've made a lot of mistakes in serving children and adults who have developmental disabilities:

- Although they are consumers and we work for them, we rarely gave them a say in what was done to -- or for -- them;

- Although many individuals with developmental disabilities learned best by imitating others, we surrounded them with people like themselves who did not have basic self-care skills, who had trouble communicating, or in other respects were not good role models;

- We expected people with developmental disabilities to live in places where we ourselves would not live -- and were amazed when they rebelled.

***Read the following material (to the line of *****) from Paul Williams to the class. Participants have this in their manuals.***

Paul Williams Quote

As Paul Williams, an advocate from England, said:

"We have a need for somewhere homelike to live, for fulfilling occupations, for affection and appreciation, for a chance to give of our best. We have emotions of sadness, happiness, anger, shame, joy. We believe we have the same rights as you to adequate housing, security, a fair day's pay for a fair day's work, and a right to determine the pattern of our own lives. We believe that we exercise responsibility to the same extent as you do. We do not abuse our freedoms any more than you do; we believe that our record of irresponsible, criminal or violent behavior, of divorce, drunkenness, ill-treatment of our fellow human beings, selfishness, cruelty or dishonesty, when compared with yours, reflects credit on us rather than the reverse.

It is often said that we like being with people of our own kind, that we need the company of our peers, that we enjoy living in communities of people with similar disabilities. Some of us do, because it is what we are used to, but we often do not feel that we have anything in common with other people with disabilities, nor do we particularly want them as close friends, nor do we want to live with them. We are rarely offered any real choice as to whom we mix with, so we are very often thrown into the company of other people with developmental disabilities and we develop skills of mixing with each other and accepting each other's company -- we probably have greater skills than you in accepting people with disabilities in our environment. However, given a choice of mixing with people with disabilities or with you, we will very often choose you -- just as you choose you.

We are delighted when you respect us as adults and take the trouble to listen to our verbal or non-verbal communications. One of the best ways in which you can do this is just to be with us sharing experiences with us. We generally respond very well when you are just sitting with us, talking to us, or engaging in everyday things with us like washing up or watching television or working or eating. We are very grateful to you when you teach us new things or organize special events for us, but really we would often prefer that you became our friends rather than our teachers or our leisure organizers. We want to be involved in individual relationships with ordinary people doing ordinary things. Take us to the seaside by all means, but come back and sleep in the next bed afterwards. Teach us how to button our clothes, but please come and share a meal with us also. By all means assess our abilities and interests, but sit and tell us about yours as well. Only in this way will our disabilities be reduced -- and your disabilities be reduced, too."

********************************************************

***Objective 1:***

***Discuss and compare periods of history in relation to the way individuals with developmental disabilities are viewed.***

Objective One

# HISTORY

HISTORY

***As you present the following outline on historical issues, involve the large group in a discussion on the historical perceptions of people with developmental disabilities. Be sure to discuss the following points:***

- ***The sequence of events that occurred: e.g., there were no institutions before 1850; period during which attempts were made to make them better; etc.***
- ***How famous individuals and families helped in shaping legislation and public attitudes.***
- ***How parents influenced the shaping of the service system.***
- ***What is meant by the term "disillusionment" and how it historically affected further changes in the lives of people with disabilities.***
- ***How historical role perceptions influenced today's world.***

**SHOW** ***Transparency 2.1 (Historical Outline)***

Transparency 2.1
(Historical Outline)

# HISTORICAL OUTLINE

| | |
|---|---|
| **1790 -- 1850** | Positive attitudes, optimistic outlooks on the future. |
| **1850 -- 1890** | The attitude of "We Need To Protect Them" begins. Institutions start, become custodial. |
| **1890 -- 1910** | Backlash organized against immigrants, Native Americans and others, including people with developmental disabilities who are seen as "different." |
| **1910 -- 1930-40's** | Negative images persist. Development of huge institutions -- warehousing of people in "snake pits." Horror movies popular depicting individuals with developmental disabilities in "villain" roles. |
| **1940-50's--1950's, early 60's** | Parent groups begin and start small "activity" centers. Famous parents lend support. Parents get upset about conditions in institutions and the lack of community services. |
| **Mid 60's -- Mid 70's** | Parents agitate. Institution exposes (Willowbrook in New York, Partlow in Alabama, Pennhurst in Pennsylvania, etc.)-- helped by professionals in the field (superintendents, etc.) |
| **1970's -- 1980's** | The result of the previous events:<br>1) More resources flowed into institutions (more staff, clothing, food, etc.). Environment improved.<br>2) Resources didn't solve problems. Downswing in attitude (disillusionment) -- movement toward deinstitutionalization.<br>3) Start of new community services -- for |

both people coming into the community and enlargment of services. Much voluntary parent effort.

**The above three events occurred simultaneously**

**Late 70's -- early 80's**

1) Improvements in institutions.
2) Excitement about community programs.
   - Institutional returnees "blossoming."
   - Families glad to have people back in their own communities.
   - Success stories concerning jobs, schools, places to live, etc.
   - Community agencies becoming more skilled at serving all individuals, even the medically involved, behaviorally challenged, etc. Demonstrating that everybody can be served with skilled staff.

# HISTORICAL ROLE PERCEPTIONS

HISTORICAL ROLE PERCEPTIONS

As seen from the historical overview, throughout history society has developed certain perceptions of individuals with disabilities. Some of these are discussed in the following section.

***Remember to emphasize that role perceptions influence the behavior of people toward children and adults with developmental disabilities. Role perceptions have also influenced the kinds of buildings constructed to serve those people.***

**SHOW** *Transparency 2.2 (Role Perceptions)*

Transparency 2.2
(Role Perceptions)

### *SUBHUMAN ORGANISM*

Subhuman Organism

- Perceived as "vegetables, animals"
- Proposals to "harvest" organs from children with anencephaly
- Buildings constructed like zoos with ceramic walls, terrazzo floors, etc., for ease of maintenance and cleaning

### *OBJECT OF PITY*

Object of Pity

- Limited expectations
- No assumption of potential for growth and development

### *OBJECT OF RIDICULE*

Object of Ridicule

- Court jesters in the middle ages were people with mental retardation or mental illness
- Jokes and cartoons about "morons," "idiots," "retards," etc.

### *UNSPEAKABLE OBJECTS OF DREAD*

Object of Dread

- Hunchback of Notre Dame, John Stienbeck's "Lenny" in Of Mice and Men, Captain Hook in Peter Pan, etc.
- Inability of people to understand differences between mental illness and other disabilities
- The public's fear resulted in environments constructed like jails or prisons or zoos
- Emphasis on controlling the person

### *HOLY INNOCENTS*

Holy Innocents

- Belief that God will reward us if we are kind to people with developmental disabilities
- "I do this for you, not because you deserve it as a matter of right but because I'm going to get something out of it" attitudes
- Does not see the person with disabilities as equal, encourages dependency

### *ETERNAL CHILD*

Eternal Child

- Mistaken use of the MA (Mental Age) in intelligence testing as an indicator of emotional maturity
- Treating adults as children, e.g., forcing adults to go to bed early
- Use of children's toys or educational equipment with youth or adults
- Inappropriately childish dress, or talking to a person as though they are a child
- Reduced expectations and perpetual dependency

### *SICK PERSON*

Sick Person

- Belief that all people with developmental disabilities are ill and need medical attention
  Note: While it is true that sometimes people with disabilities do need medical support, it is almost never a permanent condition.
- Employment of people with medical training and emphasis on "therapy"
- Environments that look like and are run like hospitals
- Heavy emphasis "clinical" work with people, e.g., "the goal is to fix them up, cure them, or make them well."
- Heavy emphasis among staff on status differentials, e.g., degrees, titles, etc.
- Preoccupation with first aid, hygiene, bodily functions, etc., and reduced contact with the normal world

### *MENACE TO SOCIETY*

Menace to Society

- The belief that people with mental retardation and other disabilities will procreate and will produce millions of "defective" people.
  examples include; Hitler's Germany, sterilization laws in the U.S. during the 1930's and 40's,
- Includes belief that men and women with mental retardation are sexually promiscuous and a threat to children

***OBJECT OF CHARITY***

- Jerry's Kids"
- Subjecting people with disabilities to humiliating charitable drives which often benefit the fund raisers more than the people intended to be helped
- Assumption of life-long dependency

Object of Charity

# OTHER MISCONCEPTIONS HISTORICALLY PERPETUATED

MISCONCEPTIONS

**SHOW** ***Transparency 2.3 (Misconceptions)***

Transparency 2.3 (Misconceptions)

**Certain beliefs and misconceptions about people with developmental disabilities have been, and still are, commonly found in our society. The following misconceptions have been historically perpetuated.**

## ✓ A Life of Complete Dependency

Complete Dependency

Not too many years ago it was a common belief that people with developmental disabilities were destined to a life of complete dependency; that they could not learn, and that the best thing to do was to care for them because they would never be able to care for themselves. Often, this meant either living at home with no support or living in an institution with many other individuals with developmental disabilities.

Today we know that even people with severe and profound developmental disabilities can learn more than ever thought possible. They can perform useful work, with support if necessary. They can enjoy normal patterns of life.

Recent advances in technology such as assistive mobility and communication devices and computerized aids are also enhancing learning, independence and productivity for many people -- regardless of their degree of disability.

## ✓ Mental Retardation Equals Mental Illness

Mental Retardation Equals Mental Illness

Some people equate mental retardation with mental illness. While it is true that some people who have mental retardation also have mental illness, the percentage of occurrence in people with developmental disabilities is no greater than the percentage in the general population. Mental retardation is not mental illness.

## ✓ All People with Mental Retardation Act Alike

All Act Alike

Many people still believe that all people with mental retardation are alike. We know this is not true. We know that everyone is an individual, that all people are different no matter what their degree of disability. If people with mental retardation appear to behave in similar ways, it is probably due to the fact that they have traditionally shared a common environment. An environment that happened to be very different from the environment that you and I share. We would probably behave differently also if we spent most of our lives away from society.

## ✓ A Person Can Function to the Extent of his/her Mental Age or IQ

Ability is Only As Good as IQ

People with mental retardation are often identified by their mental age or their I.Q. We know today that you do **a great**

**disservice to individuals when you limit their potential** by delivering services based on mental age or an I.Q.

**You do a great disservice to an individual when you limit his or her potential!**

All people can learn to function in the community no matter what their I.Q. Some people will need more support than others, but no one should be limited or held back from participating in life because of an I.Q. level or a mental age. All people deserve to be part of the mainstream of society. Individuals have **Essential Humanity**. If someone has lived fifty years, he or she deserves the respect and treatment given all fifty-year-old individuals no matter what his or her mental age.

## ✓ People with Developmental Disabilities should have "Special" Environments

"Special" Environments

Today, society is finally starting to accept the fact that all people deserve a free life guaranteed by the constitution -- including people with mental retardation. We are seeing children moving from segregated "special" schools to regular classrooms where they receive an education with their non-disabled peers. We are seeing people with developmental disabilities living in normal environments, working at normal jobs, leading normal lives.

**Don't develop preconceptions. As you begin, or perhaps continue, your work with people who have developmental**

**disabilities, you will be working with a varied group of people.** Individual strengths and weakness must be taken into consideration. Some will seldom need more than a question answered or occasional assistance doing a new task. A few people will need continuous physical care twenty-four hours each day and will be unable to perform any task. Some people will need assistance only during certain times in their lives while others will need support throughout their lives.

## SUMMARY

SUMMARY

**Each individual is a unique, one-of-a-kind person with his own likes and dislikes, temperament and personality.** Most need only a small portion of help. Most are able to actively participate in their community and contribute as fully as any other member of society. While they may have disabling conditions, with the appropriate support and assistance, they need not be severely limited by those conditions.

# PRESENT HISTORY

## The Parent Movement -- 1940+

PRESENT HISTORY

The Parent Movement

Handouts 2A - 2D

**HANDOUT** ***Handouts 2A-2D***

**PRESENT**

In the 1940's, parents began to seek each other out and band together, forming small self-help groups in cities and towns across the country. The stigma associated with one disability, mental retardation, was so strong that one editor of a local New Jersey newspaper refused to publish a personal advertisement in which a mother was trying to make contact with other parents of children with disabilities.

But parents persevered and did connect with each other. They set up cooperative day-care centers, -- places where they could cover for each other. They could leave their child for a few hours to go shopping, spend time with their other children, or simply have the luxury of a few free hours to do whatever they wanted. Most services were provided through charity and parent volunteer labor; bake sales and auctions raised funds and churches donated space.

Almost all of the parents had been told by professionals that they should institutionalize their children because of the severity of their disabilities and the difficulty the families would face in caring for them. However, many parents chose to keep their children at home as long as they could. They sought out other professionals who were willing to work with their children.

**Parents realized their children's potential.** Some parents had been told that their sons and daughters would never sit up, never walk, never feed themselves, never communicate, never recognize their parents. However, with good teachers, therapists, and lots of work by their families, the children did progress and did learn to do those very things. When parents saw this happen, they knew their children's potentials were greater than they had been told. They also learned that often professionals simply were not able to accurately predict what might occur in their children's lives.

They learned how to tell what a good program for children with severe disabilities should look like. They learned to recognize the kinds of techniques that were successful -- even with children with very severe disabilities, -- and the kinds of techniques that didn't work.

As the years went by, the demands of providing care for their children -- while at the same time working as advocates -- began to tire parents. Some children had physical needs that were severe and required help with all life activities; eating, toileting, walking, etc. Others had behavioral issues that required constant effort and attention. Some children were very poor sleepers and required almost 24 hour attention. Some families began to experience financial problems because of the expense of caring for their children. Other parents developed stress-related health problems. Marital relationships suffered.

**Families helped each other as best they could** but the difficulties of their own situations didn't leave much energy left over to help anyone else. Finding affordable child care (since parents had to pay for it) was almost impossible. There were very few people willing or trained to care for their children's needs.

**Some parents experienced feelings of guilt about not spending enough time with their children who had no disabilities. Unfortunately, many professionals diagnosed**

**these kinds of feelings -- which were based on the reality of lack of support and being tired -- as guilt feelings related to giving birth to a child with a disability.** Thus, when psychologists, social workers, psychiatrists, and others counseled parents, they saw the solution to the problems that parents were experienceing as that of getting rid of the child with disabilities rather than providing needed support and services.

## The "Association for Retarded Citizens" (The Arc)

The Association for Retarded Citizens (The Arc)

The "Association for Retarded Citizens," which had been formed in 1950 as the Association for Retarded Children, was instrumental in leading the movement for both institutional reform and, subsequently, for deinstitutionalization and the creation of new community alternatives.

Today, this group is called The Arc. The Arc changed its name at the 1991 National Convention, dropping the term "retarded" because of the connotations associated with that word. Many parent members have sons and/or daughters with conditions that require the same services as children/adults with mental retardation -- but their children are not mentally retarded. They did not want their sons or daughters to carry another label on top of the ones they already have.

**It should also be noted that much of the support for the Arc's name change came from self-advocates who consider the term "retarded" a stigmatizing label.**

The evolving advocacy of this organization, as well as other parent organizations, played a major role in defining each decade's standards for programs serving people with developmental disabilities.

**The Arc organization has been particularly influential** in the establishment of improved educational, residential, and support services for persons with developmental disabilities. For example, in the 1950's, the Arc called for restrictions on the size of institutions. In the 1960's, it assisted with establishing minimum federal and state standards for residential care facilities. In the 1970's, it passed a resolution to recommend "residential facilities consisting of small living units, each replicating a normal home environment to the closest extent possible" and "that such residential facilities take absolute precedence over further capital investments in existing or large scale institutions." In the 1980's, it supported legislation to shift Medicaid funding from institutional settings to the community.

**The Arc also has been an active plaintiff** in federal and state court cases involving the rights of citizens with developmental disabilities and their:

- Right to treatment
- Right to free and appropriate public education
- Right to the least restrictive alternative environments.

## Other Parent Groups

Other parent groups

Other parents have been equally active in promoting education and related services for children and youth with disabilities. In addition to the Arc, parent groups like the Autism Society, United Cerebral Palsy Association, and the Association for Children and Adults with Learning Disabilities have actively pursued education and related services for people with disabilities.

## Help From Policy Makers -- 1950's, 60's, 70's

Help from policy makers

Across the country in the 50's, 60's, and 70's, parents were the driving force behind the growth of services and humane philosophies. Parents were outspoken lobbyists for the rights of their children. Famous parents and family members such as John F. Kennedy (sister), Hubert Humphrey (granddaughter), Pearl S. Buck (child), and Roy Rogers and Dale Evans (child) added their voices to those of other parents. Their public acknowledgements of a family member with mental retardation went a long way toward reducing the stigma attached to this population. Those same acknowledgements also gave legitimacy to the requests of parents who had children in the institutions and in the community.

## DISILLUSIONMENT

Disillusionment

With increased funding, some changes did occur. People were clothed, professionals hired, direct care staff were trained. But even with these improvements, parents and others began to realize that even increased funding for the institutions did not change them. Because of their special needs, their sons and daughters needed individualization -- they had unique needs that could not be met in congregate living environments.

For example, children who didn't have verbal ability had other ways of communicating their needs; ways that the parents and family members had come to understand. They might make noises or make certain faces, or perhaps gesture with their hands or arms. Staff working on the wards of institutions could not possibly learn all of the characteristics of the children they were serving.

It became clear that the larger the number of staff working with individuals with disabilities, the harder it was for the employees to become familiar with each individual's unique characteristics.

Despite an infusion of new resources, horrible conditions continued to exist in some institutions and these resulted in exposes throughout the country. In New York, Senator Robert Kennedy toured Willowbrook and expressed anger at the conditions he saw there. In Alabama, a federal judge ordered that state to do a massive overhaul of its Partlow institution. In Pennsylvania, a major lawsuit was filed demanding the closure of the Pennhurst institution.

**SHOW**

***Video: Willowbrook***

***"Willowbrook" is a highly evocative video. Be sure to make the participants aware that they will probably feel a variety of emotions during and after viewing this film. The ensuing discussion may be highly emotional so be sure to:***

- ***Allow enough time after viewing the film to permit all participants the full expression of the emotions they have felt.***
- ***Make sure that no one is "shot down" or teased for expressing their beliefs during this discussion period.***
- ***Make the point that this film is shown not to tell them "what" to think, but to encourage them to think. Make the statement that "Human potential is like ice; if you leave it alone, it melts." People will lose their potential and abilities if left in such conditions.***
- ***You may also make the point that "There is danger in change, but there is also opportunity!" with the group.***
- ***Emphasize that you could have gone anywhere in the United States at this time and seen conditions similar to the ones at Willowbrook.***

Video:
"Willowbrook"

# THE OKLAHOMA EXPERIENCE

THE OKLAHOMA PARENT
EXPERIENCE

***Before beginning this section, ask the participants if they believe that Oklahoma followed the rest of the nation in the evolution of services.***

## Institutions Today

Based on public attention, media exposes and federal lawsuits filed on the behalf of individuals living in institutions, changes were mandated.

Focus on improved physical conditions, education, and training experiences to enhance the capabilities of individuals became a major requirement for continued federal funding of state institutions.

Congregate public facilities are still serving a large number of people in Oklahoma. Until community alternatives can be developed, they remain a residential option for a sizable number of people in Oklahoma. The staff at both Northern Oklahoma Resource Center at Enid (NORCE) and the Southern Oklahoma Resource Center at Paul's Valley (SORC) are striving for full inclusion and participation in local communities for individuals who call these facilities home.

Regardless of the environment in which staff and people with developmental disabilities operate, Oklahoma remains committed to making the lives of people with disabilities as normal as possible.

Institutions today

## PRESENT

The Oklahoma Parent Experience was the same as parents in the rest of the country, with one important exception. Community services were much later arriving here than elsewhere. By 1985, because of the lack of community services, many parents and their children were struggling to maintain family integrity.

Parents had worked very hard over the years to help get programs started but services were sparse and erratic. In one case, the ultimate irony occurred. The administrator of a child care program which the parents themselves had started decided to exclude their children "because their disabilities were too severe."

Virtually all recreation programs in Oklahoma, even those for children with disabilities, excluded children with severe disabilities. Often, when parents went to community agencies to try to get such programs started or to try to persuade existing programs to include their children, they were told that an institution was where their children belonged.

As their children grew older, parents began to worry about what would happen to their children when they were no longer able to care for them. They were haunted by the questions: "What will happen if my child outlives me?" "Who will advocate on behalf of my child?" "Who will monitor my child's welfare?"

They were wearing out.

## The Oklahoma Deinstitutionalization Experience - Hissom

Deinstitutionalization - Hissom

In 1963, the Oklahoma State Legislature transferred the two existing state schools for persons with mental retardation (Enid and Pauls Valley) to the Department of Human Services from the State Board of Mental Health. Both the Enid and Pauls Valley facilities had served varying functions as state institutions since early statehood. At the time of the transfer, The Hissom Memorial Center (THMC) was still under construction. THMC, serving residents of northeastern Oklahoma, opened in March 1964. In its early years of operation, THMC was believed to be a state-of-the-art program. Its buildings were used as a model for others throughout the country during a period in which the "make institutions better" philosophy existed.

However, parents came to realize that more staff and better buildings didn't compensate for the inherent flaws of congregate living. But, while other states had begun to develop group homes and other community-based options in the 1960's and 70's, services in Oklahoma remained primarily institutionally-based. For example, prior to 1981, only three group homes existed in the state. In May 1981, the state finally funded 15 group homes.

In 1983, a plan was developed to initiate an array of community-based services. Fifteen additional group homes were funded. Workshop funding was increased by the state and an application was prepared for federal funding of community-based supportive, residential and vocational services.

**HANDOUT** ***Handout 2E - Closures of State Institutions***

Handout 2E
(Closures of State Institutions)

**SHOW** ***Transparency 2.4 (Closures)***
***Transparency 2. 5 (Line Graph - Movement)***

***Discuss with participants the change in the rate of population and numbers of institutions from 1960 through projected 1995. Ask, "What does this mean?" "What do these trends suggest in relation to services for individuals with developmental disabilities?"***

Transparency 2.4
(Closures)
Transparency 2.5
(Line Graph)

## The Homeward Bound vs. The Hissom Memorial Center Lawsuit

Homeward Bound vs. THMC
Lawsuit

In 1981, several Oklahoma parents who were frustrated by the lack of family support and the need for more community options formed an advocacy organization which they called **Homeward Bound**. Homeward Bound's original purpose was to provide services for children and adults with severe, multiple disabilities.

At that time, there were no out-of-home placements for an adult with severe, multiple disabilities except in a state institution or in one of a few nursing homes. There were other places for people with mild or moderate mental retardation and some facilities would take people who also had less severe physical disabilities. However, all those excluded people with disabilities as severe as the Homeward Bound parents' children.

**The Homeward Bound supporters worked for several years** with anyone who would listen to them concerning community services. They found that other states provided services using money from Title XIX Home and Community-Based Waiver (a federal program that allowed states to obtain federal funding which had previously been limited to the operation of institutions).

They explored the possibility of getting money from private foundations, but those foundations they contacted were unresponsive. They decided to wait for things to change.

**Things did change.** Rader, the long-time director of the Department of Human Services, left. The interim director, Henry Bellmon, brought in new leadership and created a new unit to serve people with developmental disabilities.

Problems continued to exist in the institution. The parents again drew upon their advocacy experience and began to agitate for change. They wrote to the new state leadership and asked for help and were assured that the problems would be corrected. But, nothing happened except their children continued to have multiple needs that weren't being met in the institution or in the community. Eventually, all of the children of the Homeward Bound group ended up at Hissom.

**When one Hissom child experienced such severe neglect** that he nearly died, parents took action. They went to the district attorney, the Protection and Advocacy Agency, Office of Handicapped Concerns, and the Child Abuse Hot Line for aid, but no one was willing or able to help. The parents were referred to the Oklahoma Commission on Children and Youth -- which did investigate. Their findings showed severe neglect but the Department of Human Services did not respond to the report.

**Tulsa media investigated one mother's allegations about her child's neglect.** Reporters checked public records and found that two of the Homeward Bound parents had filed a lawsuit against Hissom to gain access to their children's records. One Tulsa newspaper expanded their story to a series of articles titled "Wasting Away in Oklahoma" which told the story of institutions in Oklahoma.

The parents expected to hear a public outcry as a result of the articles -- but were disappointed. At this point, they decided to formally reactivate the Homeward Bound organization; this time as an organization to develop systems advocacy to obtain services for people with severe disabilities in the community.

**They also began to ask for meetings with public policy makers** to try to convince them that there were dangerous problems at Hissom and that the solution would be to provide services in the community for people with severe disabilities.

**Parents also contacted state and national organizations** seeking help. Oklahoma organizations were unresponsive, but national organizations provided information about ways to effect change. The parents became convinced that the only way to get permanent change was to file a class action lawsuit against the state.

**The Homeward Bound parents were referred to the Public Interest Law Center of Philadelphia (PILCOP).** This law firm had handled other deinstitutionalization lawsuits in other states (they had helped close the Pennhurst institution in Pennsylvania). PILCOP contacted Louis and Pat Bullock, two Oklahoma attorneys who had been successful in other human rights cases, and asked them to join in representing the parents in Oklahoma.

A class action suit was filed in Federal District Court by Homeward Bound, Inc., and six named plaintiffs on May 2, 1985. The suit alleged that Hissom was a dangerous place to live. It requested that the state provide services to all plaintiffs and members of the class (generally speaking, the class refers to those people who were living, or had lived, at Hissom while the lawsuit was going on) in the least separate, most integrated community setting appropriate to their needs.

Testimony was heard in the U.S. Federal Court in Tulsa by Judge James Ellison. Testimony was given by numerous witnesses, experts, advisors, and other parties.

However, not all parents of residents in the institution agreed with the plaintiffs. About 120 parents joined as "intervenors," attempting to assure that Hissom remained open as an option to the community.

**On July 24, 1987, the Court issued its Findings of Fact and Conclusions of Law and the Court Plan and Order of Deinstitutionalization.** The latter defined the members of the class, set out a comprehensive plan of community services, and established a four-year timetable for placing all Hissom residents into the community. On October 21, 1987, the Court entered the judgement in favor of the plaintiffs. The state filed an appeal. A monitor was appointed to oversee the Plan of Deinstitutionalization.

Later, the state's appeal was dropped and the parties entered into a Consent Decree which was adopted by the Court on February 1, 1990. The Consent Decree superseded the previous orders, included plans for provision of community services, limited case manager's case loads, provided a schedule for placing all class members in appropriate community settings by October 1, 1994, and targeted the discharge of all remaining residents from Hissom by October 1, 1993.

It also provided for the replacement of the Court Monitor by a three-member Review Panel of professionals who had experience in developing community services and closing institutions.

**While the case only affected people who had lived at Hissom**, it was nevertheless a significant factor in Oklahoma's shifting emphasis away from institutions and toward normal community lifestyles for people with disabilities.

**All because of a handful of people.**

### Affect On Families

**EXERCISE** ***Exercise: "Reasons"***

***Before presenting this section, have the participants break into small groups of 3-5 people. Ask each group to write down three reasons why a family would want their child moved out of an institution and into the community setting as well as three reasons they would want to leave their child in the institutional setting. After giving them a few minutes to do this, bring the group together and have them present their findings. List these on a flip chart. Use this list to lead into the presentation of the next section.***

Exercise: "Reasons"

**PRESENT** It should be noted that many families were comfortable with the services provided at Hissom and were frightened and angered at the prospect of its closure. Other families were eager for their relatives to participate in community-based programs. All in all, there was much stress on all families because of negative press and the reactions of families with conflicting viewpoints. Some of the families who initially opposed moving their relatives from Hissom changed their minds after seeing the success of others in their new community residences.

It should also be noted that the Hissom residents who have moved have adapted well and have grown in their new environments. They have taken pleasure in discovering the new things that they can do.

## SUMMARY

SUMMARY

The nation has come a long way in the way society views people with disabilities. Oklahoma has come a long way also. However, we must always be aware that if "we do not learn from the past, we will surely repeat it."

## SHOW

***Video: Rumania's Children***

Video: "Rumania's Children"

***This video may also evoke much emotional discussion from the group – there will many people affected by the conditions depicted. However, the showing of Rumania's Children is important in that it illustrates the concept of "it is not that far away." This was filmed in 1990 - not that long ago. We've come a long way and we have learned many things, but as the misconceptions we have discussed show us, it is easy to fall back into old roles and old beliefs. As Santayana states, we must learn from the mistakes of the past if we do not wish to repeat them. We must be vigilant in seeing that the conditions depicted in this program do not occur ever again.***

- ***Make the participants aware that one of the main points consistently mentioned is that there were many "normal" children caught in this system and that the goal is want to find and "save" them. Make the point that if conditions were this horrible for "normal" children, how much more worse would it be for children with disabilities?***
- ***The trainer should make watching "Rumania's Children" a learning task. Ask the participants to watch for and list as many of the role perceptions and historical misconceptions as they can find. This will also aid participants in separating emotional reactions from the concepts presented in the video.***

## INSTRUCTOR QUESTIONS

1. Do you believe the old adage, "Those who do not benefit from history are doomed to repeat it? Why or why not?

2. In Stage One, "The Parent Movement," the common practice of professionals was to tell parents what concerning their child's disability and its affects on that child's potential?

3. Professionals often diagnosed parent's tiredness and depression as what? What was the real underlying cause?

4. List three policy makers that helped the parents' cause.

5. What effect did exposes' have on influencing policy making and legislation?

6. What was the original name of the Arc, and why was it changed?

7. What was, and is, the major role of the Arc?

8. Did the parent movement in Oklahoma differ from the national movement?

9. What effect did the court decision have on families?

***Objective 2:***
***Discuss the lessons we have learned from history regarding congregation and congregate settings.***

# CONGREGATION

CONGREGATION

Why have congregate settings for people with disabilities not worked? **It's not because of the people who work in them.** Those people are no different than community service workers. They are just human beings. They care. They work hard. But there is no system that is perfect -- that is why we are constantly trying to improve and move towards that illusive goal of excellence.

## ARGUMENTS ON WHY CONGREGATION HAS NOT WORKED

WHY CONGREGATION HAS NOT WORKED

**SHOW** ***Transparency 2.6 (Congregation)***

Transparency 2.6
(Congregation)

- **If you put people into groups, you subordinate individualization for the greater good of the whole.**

Subordinate Individualization

Whether it is an army barracks, a sorority house on a college campus or a dormitory, you must give up individuality to some extent for the sake of the larger group. You might have to eat at the same time, take showers at certain times, go to bed at specific times.

As the severity of the disabilities increase, the more personalized an individual's program must be. If the goal is "individualization," then congregate arrangements won't work.

- **Imitation and role modeling are powerful learning tools.**

Role Modeling

Sometimes, role modeling and imitation are the only ways a person can learn. Therefore, we need to surround people with severe disabilities with the most positive role models possible.

People with limited cognitive abilities also have limited number of ways in which they learn. **The most profound and effective way of transferring knowledge is by applying real skills in real environments.** Hence the need to learn to shop in a grocery store by shopping in an actual grocery store.

**The importance of role models and natural environments cannot be overemphasized.** If you want an individual to be able to eat in a proper manner at a restaurant, you must take them to a restaurant so that they can learn in a real environment. If you want him or her to model a certain style of behavior, you must allow him or her to be around individuals who have behavior that are appropriate.

In congregate care situations, the person with disabilities is often surrounded by people who can't talk, people who aren't able to dress themselves, people who aren't able to walk or feed themselves. From these available models, the individual often learns inappropriate behaviors and fails to develop necessary skills such as communicating and taking care of their physical needs.

### ☞ Absence does not make the heart grow fonder.

Absence Promotes Segregation

The "**out-of-sight, out-of-mind**" philosophy has been in existence in the treatment of people with developmental disabilities for hundreds of years. It is easy to forget something -- or someone -- when you are apart. New relationships develop. Old ones are forgotten. Families re-constitute themselves without the absent member. Soldiers away from home often receive "Dear John" letters because of their absence.

Often, when parents leave a child at a congregate care facility, they at first visit constantly. This slowly reduces down to once a week, then once a month, then once every three or four months until finally, visits are rare or none at all.

**OUT OF SIGHT IS TRULY OUT OF MIND!**

Absence **does not** make the heart grow fonder. Absence promotes segregation. Absence allows us to forget.

### ☞ Skills need to be taught in the environments where they will be used.

Skills Learned in Environments Where They Will Be Used

Skills need to be taught in settings where they will be used. It is difficult to transfer learned skills from an artificial environment to a real environment. Children and adults with mental retardation often have special difficulty transferring knowledge or behavior or skills learned in one place to another. Therefore, if you want to teach a person to eat at McDonald's, take him or her to McDonald's and teach the appropriate behaviors **in the environment where they will be used.**

☞ **"Special" often isn't. "Pre" means never.**

"Special Environments"

People with disabilities should not be relegated to "special" environments. "Special" schools, "special" homes, "special" classes encourage separatism and segregation. Remember, one of the best quotes you may hear is that **"Pre" means Never**. Pre-vocational, pre-educational -- these describe situations that may, however well intended, prevent the individual from entering into a non-segregated environment in one form or another.

☞ **Bigger isn't better or cheaper.**

Bigger Isn't Better

People used to think the bigger the better. It was assumed that if you brought more experts closer together, it would be easier to deliver more services.

People were segregated into large groups living in institutions under the guise of "larger is better -- better medical care, better facilities, better conditions in general." The belief that "they will be happier with their own kind" prevailed. Individualization was discouraged for the greater good of the group.

We paid a high price for that centralization. As institutions kept getting bigger, people lost touch with each other. They lost intimacy, lost identity, lost power, lost control, they even lost their lives.

And the sad part was, it wasn't any cheaper because by removing people from their community we lost all of the "helping hands" -- friends, neighbors, co-workers who provided support. We also had to pay for construction of buildings, gyms, swimming pools -- that were already available in the person's home community.

Now we know better. We have a new way to go. Individualization is better. If people with developmental disabilities are to live and work in a diverse community, they must reach out, depend upon others and in turn, live varied and valued lives.

It is also important that these scaled down homes be in harmony, both within themselves and with their environment. There should be no clangers that signal an improper fit between the place and the neighborhood, or between the outside appearance and the inside function, or between the interior decor and the people.

When all is said and done, the acid test that can be applied by you as a human being to places where people with disabilities live, work, play, or learn is:

**Would you sleep,**
**eat,**
**work,**
**and live here?**

# SEGREGATION

SEGREGATION

## ■ Lack Of Contact -- The Importance of Accessibility

Lack of Contact

People with disabilities are sometimes present in the community but are not really allowed to participate.

Often, they have often not been given the opportunity or the support necessary to do their best at home, at school, or at work. **Sometimes the barriers to their integration (presence), to their inclusion (presence and participation) in our world are physical.** People who use wheelchairs cannot access a building if there are no ramps or elevators. They can't communicate with us because they haven't been provided with an electronic or manual communication device.

## More Segregation - Environments

Environments

An environment that is artificial, manufactured, isolated, or markedly different from the norm will frustrate the development of "normal" social living skills, or even encourage development of really "different" behaviors.

For instance, people in a segregated environment will learn the skills necessary to live there. They will learn how to stand in line, how to wait for instructions, how to be dependent, how to let others make decisions about their lives.

An example of segregation is seen when educational professionals, in concentrating on "special" needs, place children with developmental disabilities in separate classes and schools. Such segregation begins at the preschool level, when communities provide separate recreation programs and separate summer camps.

**SHOW** ***Transparency 2.7 (Lack of Contact).***

Transparency 2.7
(Lack of Contact)

***Explain how the lack of contact with individuals with developmental disabilities leads to a lack of knowledge about them; about what they need, about what they desire, and about what they feel. This lack of knowledge results in a fear of the unknown which is unjustified, but the fear itself justifies our attempts at distancing these individuals from interaction with society and results in deprivation and segregation.***

**Lack of contact =**
**Lack of knowledge =**
**Fear of the unknown =**
**Justification for distancing (Us/them)**

**SHOW** ***Transparency 2.8 (Segregation Reinforces...)***

Transparency 2.8
(Segregation
Reinforces)

Segregation reinforces the belief in others that those who are segregated **need** to be segregated; they benefit from it.

**It reinforces fear of people with developmental disablities,** and the belief, that if society has seen fit to put these people away, it must be for a good reason -- they must represent some type of threat. We cannot form an objective opinion of them. Lack of understanding gradually metamorphoses into a belief that they must be menacing or unsociable.

**The barrier to inclusion may also be the attitudes and expectations of others.** Frequently, people have been segregated from their communities and congregated together in large institutions with others who also have developmental disabilities. This may have been done with the best of intentions but the results were disastrous.

The results of deprivation, segregation and congregation are wrong, but not just for the people removed from society. The wrongness bends back upon the community until it forms a circle. The people were removed from the community because society perceived them as carrying a stigma. And the act of removal reinforced the perception of stigma, which further rationalized the removal. And the rest of us lose the opportunity to interact with an entire segment of society.

We can integrate people with developmental disabilities back into everyday community life. We can ensure their right to enjoy all the things that we value for ourselves.

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## INSTRUCTOR QUESTIONS

**10. Define the terms segregation and congregation and discuss the differences between the two.**

**11. List three reasons why congregate environments have not worked.**

**12. What is meant by the term "lack of contact?" How does it apply to segregation?**

**13. How can well-educated professionals be caught up in the previous concepts?**

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***Objective 3:***
***Compare and discuss the differences between legislative rights and other rights in relation to individuals with developmental disabilities.***

*Objective Three*

***After introducing this section, have participants write down five rights that they enjoy. Tell them to save these; they will refer to them at a later date. Then present this section.***

# RIGHTS

RIGHTS

**In Oklahoma and throughout the United States, parents participated in the struggle for Rights.**

**It continues.**

The sequence of events in the parent movement was pretty much the same in every state:

1. Parents joining together to help each other with their sons and daughters in such activities as setting up volunteer-operated children's centers in church basements with equipment donated by community citizens;
2. An attempt to improve the institutions;
3. Disenchantment with institutions and a belief that they must be abandoned;
4. Attempts to make community services a matter of right, not privilege, by lobbying the executive branch

(governor's office) and legislative branch (state representatives and senators) and the federal government;

5. When all of that either failed or moved too slowly, they went to the judicial branch of government;

***If you are familiar with the following legislative and judicial class action lawsuits, discuss them in relation to Parent Advocacy:***

| | |
|---|---|
| ***Partlow -*** | ***Alabama case established Right to Treatment*** |
| ***Pennhurst -*** | ***Pennsylvania case that established right to Least Restrictive Alternatives and Right to Education*** |

What are the rights of people with developmental disabilities? What laws and court decisions have been written that we need to know about that established rights for individuals with disabilities?

# A BRIEF OVERVIEW AND DISCUSSION OF LEGISLATION

LEGISLATION

***The sections on legislation may tend to be confusing to many of the participants. It can be helpful if you break this information up with some light humor or a movement activity that fosters building group cohesiveness.***

**ACTIVITY** ***OPTIONAL: You may wish to divide into three small groups and allow each group to present a piece of legislation relating to individuals with developmental disabilities. Have them list and present to the group the following items:***

***1) Who the law applies to;***
***2) What rights it guarantees;***
***3) How it differs from the other laws discussed.***

## REHABILITATION ACT (1973)

Rehabilitation Act

**SHOW** ***Transparency 2.9 (Rehabilitation Act).***

Transparency 2.9 (Rehabilitation Act)

Section 504 of the **Rehabilitation Act** (1973) was the first civil rights law which guaranteed equal opportunity for more than 35 million Americans with disabilities.

The language of the law is similar to that in other civil rights acts which prohibit discrimination.

**The law mandates that:**

> "No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal assistance."

## WHO IS PROTECTED BY SECTION 504?

Section 504 covers only people with disabilities. For purposes of this law, a person is protected if they:

- have any physical or mental impairment which **substantially limits** one or more major life activities;
- have a **past record** of such impairment, but are **not presently** handicapped;
- are not handicapped and never have been but **are regarded by others** as having a handicap(s).

As seen in the first item, the definition covers much more than just mental retardation or developmental disabilities. Any physical or mental impairment is covered, as long as it **substantially** limits one or more major life activities.

**SHOW** ***Transparency 2.10 (Individuals with Disabilities Education Act)***

Transparency 2.10
(IDEA)

## THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT

(Public Law 94-142)

Education For All
Handicapped Children Act

This law guarantees the right of all children with disabilities to a free, appropriate public education and established the early intervention program. The most recent amendments were included in PL102-119. The law applies to all children (ages 3 - 21) regardless of where they live. Some of the most important features of this law are:

1. It places responsibility at the local (where the child lives) school district level;
2. It requires that as much as possible, the child be

educated in the least restrictive, most integrated setting;

3. It guarantees parent/advocate involvement in the planning process;
4. It requires that an individual education plan (IEP) be developed for each child;
5. It requires that a variety of services, such as occupational and physical therapy, health services, language training, etc., be made available if required by the child's IEP.

Originally enacted in 1975, this Act has been amended through the years since then. In 1986, Public Law 99-457 changed the title of the Act to the:

Individuals with Disabilities Education Act (IDEA)

## INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

(Public Law 99-457)

IDEA established the early intervention program for children from birth to the age of three.

Appropriate implementation of the Individuals with Disabilities Education Act will ensure that the history of exclusion and neglect shown by public schools will not be perpetuated.

Developmental Disabilities Assistance and Bill of Rights Act

## DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

**SHOW** *Transparency 2.11 (Developmental Assistance)*

Transparency 2.11 (Developmental Disabilities Assistance and Bill of Rights Act)

Established a federally assisted state program designed:

- To enhance the role of the family in assisting people with developmental disabilities to achieve their maximum potential;

- To provide interdisciplinary training and technical assistance to professionals, paraprofessionals, family members, and individuals with developmental disabilities;
- To advocate for public policy change and community acceptance of all people with developmental disabilities and their families so that the necessary services, supports, and other assistance and opportunities are available;
- To promote the inclusion of all people with developmental disabilities;
- To promote the interdependent activity of all people with developmental disabilities;
- To recognize the contribution of all people with developmental disabilities as they share their talents at home, school, and work, and in recreation and leisure time; and
- To ensure the protection of the legal and human rights of people with developmental disabilities.

## THE AMERICANS WITH DISABILITIES ACT (ADA) (1990)

Americans With Disabilities Act (ADA)

**SHOW** ***OPTIONAL - Video: Americans with Disabilities Act***

Video: "ADA" (optional)

The Act (ADA) 1990 gives civil rights protection to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations (hotels, restaurants, movie theaters, stores, pools,) transportation and telecommunications. The Act establishes deadlines for the various requirements to become effective.

Most of the requirements of the ADA were effective as of January 26, 1992. Some of the requirements do not become effective until 1994 or 1996 while others do not begin until 2010.

# OTHER RIGHTS

OTHER RIGHTS

## EXERCISE *OPTIONAL Exercise: Rights*

Optional Exercise: "Rights"

***Break into small groups and tell the participants to make a chart. On the left side of their paper, they are to list the rights they value. On the right side, they are to list the same number of rights that individuals with developmental disabilities value. Each small group is then to present this to the large group and discuss the differences between their two columns. DHS publications 90-18 (Your Rights) and 92-01 (Citizenship Rights) are excellent resources for this exercise.***

***After this exercise, lead the group in a discussion on the following rights. Make the point that these are only some of the rights we all value.***

## ✓ RIGHT TO VOTE

Right to Vote

We should strive to see that adults with developmental disabilities are able to exercise their right to share in the political process. They have the right to register and vote, and the right to organize and petition for redress of grievances.

## ✓ RIGHT TO HAVE GRIEVANCES HEARD

Right to Have Grievances Heard

People with developmental disabilities have the right to informally complain or officially protest if they are not receiving fair treatment. Sometimes we may have to help and support individuals in their efforts to do this.

People with developmental disabilities also have the right to expect certain things from us as human service workers. All employees in Oklahoma's service system should offer whatever help is needed to **empower** the people they serve in making their voices heard.

## ✓ OTHER RIGHTS

Other Rights

People with disabilities have the right to expect that we will soften and dissolve the barriers that have been erected by our fellow workers or by society. Too often we make "responsibility," "duty," "authority," "control," "professional distance," and "objectivity" more important than anything else. They are not. And too often people with special needs have been crushed and suffocated by their environments which place a high premium on such compliance.

Moving toward interdependence (**because none of us is truly "independent" of each other**), competence and control of one's own life is a great adventure. One of the ways we can play an important role in that adventure is by helping the people we serve secure for themselves the full enjoyment of their rights.

# CHOICE

CHOICE

***Discuss the differences between rights and choices.***

Rights

**What about rights? Rights are things *to which individuals have just claim.*** We have claim to legislative rights and moral rights. We have claim to fair and just treatment. We have claims to the rights guaranteed by law. But not all rights are written down as laws. These other rights can be every bit as important. As with all people, individuals with disabilities have limits on their rights. The exercise of their rights may not infringe upon the rights of others or upon their own safety or health. There are responsibilities associated with rights and choices.

**Let's look at choice.**

Choices

According to Webster's Ninth Collegiate Dictionary, **a choice** ***indicates or implies an end or purpose which requires exercise of judgement.*** In other words, making a choice requires an individual to make a decision about something based on the facts an individual may have acquired about the situation. Choice-making skills are developed, they do not just automatically appear. People must develop the process of making informed choices as well as distinguishing the difference between what is a right and what is a choice.

Pretending that choices exist when circumstances say they do not is a copout. We must work to make the right of choice real. We must make **informed choices**. All information, and options, on a subject must be presented before an individual can make a real and valid choice. If a person is living in a segregated, protected setting, and has never known any other, can that person possibly make an informed choice about whether or not he or she wants to stay there? If we ask that person if s/he would like to leave that dependent setting, are we offering a real choice?

We should be able to choose where we live -- within the confines of our ability to afford it. We should be able to choose our friends and with whom we want to live. We should be able to choose the kind of work we do, what we wear and what we do for entertainment and leisure.
Rights, freedoms and choices are valuable in and of themselves. But they lose much of their utility if we are physically unable to take advantage of them. Everyone has the right to decent health care, and we should work to see that physical disabilities are corrected if it is technically possible.

**All of us have some limits on our range of choices.** The concept of choice has sometimes been distorted to mean unlimited freedom of choice. We work, often not because we choose to, but because society will not support us totally when we can do meaningful, productive work. We take medication, not because we want to, but because we want to avoid illness or to get well. And sometimes there is no choice available as in the case of personal jeopardy, where life or health is involved, or if choice infringes upon the rights of other individuals.

Activity:
"String Toss"

## ACTIVITY *Activity: "String Toss"*

***Objective:*** *To foster group cohesiveness and to broaden an understanding of rights and choices.*

***Holding one end of a ball of yarn, tell a choice that is important to you as instructor. Tell the participants to use the lists they have made earlier and as the ball is tossed to them, they must tell a right or choice that is important to them in their daily lives. Instruct them to continue holding the yarn but to toss it to another person so that they may tell their choice. When everyone has caught the ball and told of a choice, the room will look like a large spider web. Start with the last participant and rewind the ball back to the beginning while leading a discussion on the choices we take for granted. Be sure to discuss:***

- ***Not all people have access to the same freedom of choice.***
- ***Some choices are not possible because of physical or environmental constraints (i.e. travel).***
- ***Even though rights may be guaranteed by law, can you cite examples where these rights may not be complied with.***
- ***What is an "informed choice?"***

## INSTRUCTOR QUESTIONS

**14. What is the difference between a choice and a right?**

**15. What is an "informed choice?"**

**16. Why is the right of choice a major concern to individuals with disabilities?**

***Objective 4:***
***Identify types of abuse and neglect and discuss the term "non-aversive" methods.***

# MISTREATMENT/ MALTREATMENT

MISTREATMENT/
MALTREATMENT

**SHOW** ***Transparency 2.12 (Mistreatment/Maltreatment).***

Transparency 2.12
(Mistreatment/
Maltreatment)

"**Mistreatment/Maltreatment**" means harm or threatened harm to a child's or resident's health or welfare by a person responsible for that individual's health or welfare. It may be caused by any violation of statutes, regulations, written rules, procedures, directives, or accepted professional standards and practices, which is not found to be abuse or neglect. Mistreatment results in, or creates the risk of, injury of a child or resident including (but not limited to) the following situations:

1. Conduct which evidences a reckless disregard for the health or safety of a child or resident.
2. Acts or omissions which contribute to the delinquency of a child.
3. Excessive or unauthorized use of force.

# PREVENTING MISTREATMENT

PREVENTING
MISTREATMENT
MALTREATMENT

***Make a special point that definitions associated with mistreatment/maltreatment will vary according to specific laws so the following terms and definitions are generic definitions intended to aid in the clarification of the following material.***

There are certain factors that are important to consider when discussing abuse and neglect. Individuals who have developmental disabilities are often very vulnerable, and therefore are at a high risk of being abused and neglected and must rely on others to protect them. We must be able to recognize the types of abuse and neglect and we must be able to be responsible for the safety of those we serve.

# TYPES OF MISTREATMENT

TYPES OF
MISTREATMENT

There are three major categories of mistreatment:

- **Abuse**
- **Exploitation**
- **Neglect**

## ABUSE

Abuse

The term "Abuse" means the intentional infliction of physical pain, injury or mental anguish or the deprivation of food, clothing, shelter, or medical care by a caretaker of other person responsible for providing these services.

**SHOW** *Transparency 2.13 (Physical Abuse)*

Transparency 2.13
(Physical abuse)

## PHYSICAL ABUSE

Physical abuse

**Physical abuse** is the intentional (nonaccidental use or offer of physical force by a person responsible for an individual's health or welfare, aimed at hurting or injuring the individual; or knowingly causing or permitting any person to intentionally injure an individual.

Examples of physical abuse are:

- Hitting, shoving, tripping, pushing, scratching, cutting, biting, etc.
- Using physical or chemical restraints

Some signs of physical abuse are:

- bruises and welts
- cuts, punctures, scratches
- broken bones and fractures
- burns
- human bite marks
- internal injuries
- suspicious scars
- unexplained fear of caregiver
- unexplained injuries or injuries that do not "add up"

**SHOW** *Transparency 2.14 (Sexual Abuse)*

Transparency 2.14
(Sexual Abuse)

## SEXUAL ABUSE

Sexual abuse

**Sexual abuse** is a form of physical and/or emotional abuse in which sexual activity is initiated toward an individual by a person that is in a position of power over the individual.

Examples of sexual abuse may be:
- Incest
- Lewd or indecent proposals to a child
- Child pornography
- Rape

Some signs of sexual abuse may be:
- behavioral changes
- recurrent nightmares, night fears
- infantile behavior
- unusual interest in or knowledge about sexual matters
- self-destructive behavior
- overheard sexual remarks concerning rape or abuse

Physical signs may include:
- torn or stained underclothing
- vaginal or rectal bleeding, pain, itching or swollen genitals, vaginal discharge
- vaginal infection or disease

**SHOW** ***Transparency 2.15 (Emotional Abuse).***

Transparency 2.15
(Emotional Abuse)

## EMOTIONAL ABUSE

Emotional abuse

**Emotional abuse** results from subjecting an individual to an atmosphere is which that person does not feel wanted, secure, or worthy.

Examples of emotional neglect and abuse may include:
- Constant negative atmosphere
- Extreme teasing or humiliation
- Talking down to the individual
- Threatening with physical harm
- Withholding emotional support

Signs of emotional abuse may include:
- changes in behavior
- expression of fears
- expression of suspicion
- unwillingness to talk

## EXPLOITATION

EXPLOITATION

Transparency 2.16 (Exploitation)

**SHOW** ***Transparency 2.16 (Exploitation).***

The term "Exploitation" means the unjust or improper use of the personal resources of a person for the profit or advantage, pecuniary or otherwise, of another person. Exploitation includes but is not limited to prohibited business transactions such as follows:
- Buying or selling any item or items for money or items of trade to clients
- Trading articles by force from a client
- Taking any article by force or stealing from a client
- Bartering with a client for articles or money
- Borrowing money or any item of value from a client
- Accepting articles in the form of a gift from a client

## NEGLECT

NEGLECT

Transparency 2.17 (Neglect)

**SHOW** ***Transparency 2.17 (Neglect).***

***Make sure that participants are aware of the differences between abuse and neglect.***

**Neglect** is characterized by willful omission rather than commission of an act. It is influenced by the community and cultural norms and ranges from mild to severe in form.

The term "neglect" means the failure to provide protection for a person who is unable to protect his or her own interests. It may also be the failure to provide adequate shelter or clothing or the harming or threatening with harm through either action or inaction by either another individual or through the person's own action or inaction because of his lack of awareness, incompetence or incapacity. This action or inaction either results or may result in physical or mental harm.

Examples of neglect may be:

- Insufficient diet
- Insufficient opportunity for personal hygiene
- Inadequate shelter and clothing
- Medical neglect
- Inadequate supervision

Some signs of neglect may be:

- provider has an alcohol or drug problem
- individual is fearful of a provider
- health problems - related to failure to provide care
- dehydration
- open sores

## EXERCISE ***Exercise: "The Holiday Incident"***

Exercise:
"The Holiday
Incident"

***Handout the Holiday Incident exercise to participants and give them time to read through and answer the questions on the exercise sheet. After everyone has finished, Lead a group discussion on:***

- ***What caused the incident (examine all factors – even those that may not be very obvious).***
- ***Emotional considerations and positions.***
- ***Mitigating circumstances.***
- ***Overall frustrations.***
- ***Ask "What should have been done by each person involved to prevent the incident from occurring?***

**** Information for "The Holiday Incident" is in the "Trainer's Information" section of the trainer manual.***

***Break into small groups and assign each group a type of abuse (Mistreatment, neglect, sexual abuse, etc.). Let the groups discuss the***

***causes and signs of mistreatment associated with their area. Come back into large group and discuss their results as well as the methods of reporting mistreatment. Make sure you emphasize that you have a responsibility to report suspected mistreatment and that no repercussions will fall on an employee for reporting what he or she believes is mistreatment, even if it turns out that mistreatment did not occur.***

# REPORTING MISTREATMENT

REPORTING MISTREATMENT

State of Oklahoma law requires that "any person having reasonable cause to believe that a child is experiencing abuse or neglect, or an elderly person or incapacitated adult is suffering from abuse, neglect or financial exploitation is mandated to make a report to either the Department of Human Services (Child Protection Services, Adult Protection Services, or Office of Client Advocacy) or the office of the district attorney in the county in which the suspected incident occurred.

"**Any person who knowingly and willfully fails to promptly report any abuse, neglect, or exploitation shall, upon conviction, be guilty of a misdemeanor.** Any person who willfully or recklessly makes a false report or a report without a reasonable basis shall be liable in a civil suit for any actual damages suffered by the person(s) being reported and for any punitive damages set by the court or jury."

The law also provides that any person exercising good faith and due care in making a report... "shall have immunity from any civil or criminal liability that might otherwise be incurred."

In other words, no one is excused from reporting signs of mistreatment. You must make an immediate report. This includes all direct care staff, police, doctors, nurses... everyone.

It is safe to report. You have immunity from any retaliatory action which means you cannot get into trouble with the law or at your work if you make a report and it turns out to be wrong. If you do not report something, however, that should be reported, your job may be in jeopardy and under certain circumstances, you may find yourself the subject of an allegation of neglect for failure to report.

**HANDOUT** ***Handout 2F (Reporting Mistreatment)***

Handout 2F (Reporting Mistreatment)

# To make a report call:

- **the local DHS office;**
- **or the local office of the District Attorney;**
- **the DHS Abuse Hotline**

**1-800-522-3511**

You may also call the Office of Client Advocacy at

**1-800-522-8014 or 1-405-521-3491**

## Content of Reports

Content of Reports

***Lead the group in a discussion of examples of bad faith reporting; e.g., an employee fired for improper conduct trying to get back at co-workers, etc. Go over things they might do. Also, discuss what should be included in good faith reports.***

All reports of abuse and neglect should include the following information:

- The name and address of the individual being abused or neglected;
- The name and address of the caretaker, if any;
- A description of the situation.

# GENERAL RULES FOR PREVENTING MISTREATMENT

GENERAL RULES FOR
PREVENTING
MISTREATMENT

**SHOW** ***Transparency 2.18 (General Rules)***

Transparency 2.18
(General Rules)

Wise care givers take precautions to prevent situations that may lead to mistreatment occurring. Some of these are;

- **Treat all people with dignity and respect.**
- **Do not make verbal threats. Words can turn into actions.**
- **Call for help if you are in doubt about how to handle a client or situation.**
- **Admit when you have made a mistake. The people you serve can be right about issues, just as you can be right.**
- **Get enough sleep so you are alert on the job and so your patience will remain intact.**
- **Never drink alcohol or use tranquilizing or stimulating drugs before coming to work.**
- **Don't be so preoccupied with orderliness and good behavior that control and authority are the only means used to teach clients appropriate behavior.**

**Most importantly!!! Send a clear message to those around you that you will report mistreatment.**

# NON-AVERSIVE METHODS

NON-AVERSIVE
METHODS

Sadly, the past has held a long history of abuse for people with disabilities. Aversive or physical means were often used to compel behavior. The term "aversive" is defined as causing the avoidance of a noxious stimulus. Aversive methods and behavior modification techniques were used, including the use of punishment. Untrained people were allowed to use such approaches as uncompromising holding or pushing or putting individuals in restraints without supervision. As a result, people had bones broken when they were pushed or grappled down to the floor.

Earlier we talked about programs and staff that are preoccupied with control, authority, and making sure that "clients" know who is in charge. These are indicators of staff who may either lack adequate skills or whose attitudes are not consistent with the Developmental Disabilities System.

We have learned that behavior that may appear dysfunctional or destructive is, for some people their only means of communicating their needs. Self-injurious behavior is almost always communicative; it expresses the need to get away from something, to get something, etc.

All behavior is purposeful. The key is not to blame people for what is not under their control. We need to accept the responsibility to try and figure out why the person is using that particular kind of behavior. We need to teach people less destructive methods of communication. We need to read the environment to understand why people do what they do and act the way they act.

**Oklahoma has committed itself to eliminating aversive methods. The use of physical punishment in any form is grounds for termination and possible prosecution under the law.**

***Make sure you strongly emphasize that the State of Oklahoma not only does not condone the use of aversive methods but actively opposes them. The use of such methods or failure to report such methods is grounds for termination and possible prosecution.***

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INSTRUCTOR QUESTIONS

**17. Define and discuss the four types of abuse and neglect.**

**18. What conditions may lead to incidents of abuse and neglect?**

**19. Discuss methods of preventing abuse and neglect.**

**20. What does the term "non-aversive" mean in relation to Oklahoma's philosophy of treatment of individuals with developmental disabilities?**

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## SUMMARY

## CODE OF RESPONSIBILITY

Code of Responsibility

**HANDOUT** ***Handout (Code of Responsibility)***

***This handout is in the participants' manuals. Discuss what this means to the participants in their future roles.***

We respect the dignity and worth of all individuals. We strive for the preservation of human rights. We protect the welfare of those we serve while supporting and enhancing their self-responsibility. We apply the following universal values to our work with people with developmental disabilities. These values are:

- self-determination
- doing good and avoiding harm
- telling the truth
- respecting confidential information
- keeping promises
- courtesy

We use our skills only for purposes consistent with the above values.

**We affirm that:**

- **We abstain from the non-medical use of any mood-altering chemicals while working.**
- **We do not become sexually involved with individuals we serve because this violates trust. Sexual intimacy in any form is unethical; including remarks, gestures, or anything of a sexual nature.**
- **We avoid conflict of interest -- we do not sell goods or services to individuals we serve because they may not feel they can tell us "no." We avoid dual relationships of any kind which might impair the helping relationship.**
- **We respect the privacy of the individuals we serve.**
- **We recognize the boundaries of our training and experience. We use only those techniques for which we are qualified.**
- **We neither claim nor imply qualifications exceeding those we possess.**

- We recognize that good practice is continuing education and training. Further, we hold ourselves responsible for our own personal growth.

- We are aware of the dependency/unequal power in our relationships with the people we serve, and we maintain respect for them by avoiding activities which meet our personal needs rather than their needs. We avoid bringing our personal issues into the relationship. Our responsibility is to the individuals we serve, FIRST.

- We are aware of the negative impact of racial, sexual, and disability stereotyping and guard the dignity of the people we serve.

- We respect the right of the individuals we serve to be involved in any plans made in their interests and hold ourselves responsible for involving them or an unbiased advocate when individuals cannot speak for themselves.

- When an individual's condition indicates a possible danger to self or others, we have a responsibility to immediately inform responsible parties and take reasonable personal action, consulting with others as soon as possible.

- If we possess information about possible unethical conduct of a colleague, we must take action to rectify the situation immediately.

- We act with integrity toward our colleagues, respecting their areas of competence and cooperating with them fully for the welfare of the individuals we serve. We use appropriate practices for expressing disagreement. Further, we are committed to educating our colleagues regarding effective practices.

***Objective 5:***

***Discuss the things all individuals value and relate these values to people with developmental disabilities.***

# THE THINGS WE VALUE

## PRESENT

**We value many things in our lives: our legal rights, our ability to make choices, our freedom to be protected from abuse or mistreatment. But, often people fail to remember that individuals with developmental disabilities value the same sorts of things we value.**

**Too often we take the things we value for granted.** Think of a time you were laid up from an injury. Remember how hard it was to get around, and remember how people stared at your cast? We forget how much we value mobility and inconspicuousness until we lose it. If we're lucky, it's only a temporary thing. Some people aren't that lucky.

Transparency 2.19
(Values)

## SHOW

***Transparency 2.19 (Values)***

***Using a flip chart, ask the group to:***

- ***First define the word "Values"***
- ***Go around the room and ask each person to give one example of something they value.***
- ***Ask the group to discuss how they would feel if they were deprived of the things they value.***

Think of some of the other things we value.

- We value being recognized as individuals, separate from any class label.
- We value being accepted by friends, neighbors and sales people as OK.
- We value living with people we love. A comfortable home. Good neighbors.
- We value having the opportunity to make choices and not being limited to one job, or one outfit, or one TV show.
- We value doing things for ourselves. Being as independent as possible.
- We value making our own decisions and knowing the joy of being right, or even being wrong, if we can learn from it.
- We value being respected for doing a job well, being considered competent.
- We value having friends who enjoy our company so we have the option of being included socially. To take in a Saturday night movie with the gang is a lot of fun. So is shooting the breeze during a card game.

It's difficult to imagine how you could go on living without these things. And yet, many people do. When you see someone, or a group, deliberately deprived of something that everyone values, you realize that the right to lead a normal life has been violated. All people value normal environments in which they can live, work, and enjoy life in their community.

# PRACTICAL APPLICATIONS OF VALUES

PRACTICAL APPLICATIONS

***What are practical ways you can apply the abstract concepts of values to the real world?***

There is a way to do this -- it's called the **Principle of Normalization**. This principle gives workers in the field the realistic tools they need to make environments for people with disabilities as normal as possible. It is an **application** of the concepts we have learned. To this extent, the Principle of Normalization recognizes the power of the environment on people and addresses the basic human needs that all people value.

***Objective 6:***
***Describe the Principle of Normalization; how it began and why it is called an ecological concept.***

***Objective Six***

# NORMALIZATION

**SHOW** **Handouts 2F-2G (Normalization)**

- ***Ask the group to define "Normalization." Use their contributions as an introduction to the presentation of the following material on Normalization.***

# PRESENT

**The concept of Normalization goes back to the late 1950's.** Mr. N.E. Bank-Mikkelsen was head of the Danish Mental Retardation Service. On one of his routine visits to a local institution, he was struck by the dullness of the place. He saw drab rooms, bare walls, hard and uncomfortable furniture, dormitory style bedrooms and a total lack of privacy. And the residents themselves were dressed in clothes lacking color and style.

He began to compare what he saw in their lives with what he saw in his own. He thought of the comforts he enjoyed such as sofas and stuffed chairs, spacious and colorful rooms, a private bedroom and bath. He thought of his stylish clothes and his stereo system. Along with parents of children and adults with disabilities, he began to seek ways to highlight the differences in the environments of the institution and the more "normal" environments enjoyed by the rest of us.

**The end-product of that search was the concept of normalized settings**, meaning "enabling people with mental retardation to obtain an existence as close as possible to that of everyone else."

This led to a radical shift in the way services were provided in Denmark. The struggle was on to establish a new measure for the care, education and treatment of people with mental retardation. That measure: the lifestyle that everyone else enjoys.

**The normalization principle was first translated into English** by Mr. Bengt Nirje of Sweden, in 1969, and was then further refined by Dr. Wolf Wolfensberger, at the time a college professor in Nebraska (now teaching at Syracuse University in New York).

# THE CONCEPT OF NORMALIZATION

THE CONCEPT OF NORMALIZATION

The concept of normalization stresses the use of normal environments and experiences for all people with disabilities. Normalization does not try to make people normal. Normalization does not deny that individuals with developmental disabilities often need coordinated services and supports beyond those normally available to people without disabilities. It does stress that services and supports be provided in normal environments and culturally normal ways.

Nirje expanded the concept saying "Normalization means sharing a normal rhythm of day, with privacy, activities and mutual responsibilities; a normal rhythm of week, with a home to live in, a school or work to go to, and leisure time with a modicum of social interactions; a normal rhythm of year, with the changing modes and ways of life and family and community customs as experienced in the different seasons of the year.

## Characteristics of Normalization

Characteristics of Normalization

- **Conditions of everyday living**
- **Normal rhythms**
- **Normal activities**
- **Culturally appropriate teaching strategies**
- **Integrated lifestyles**

These are explained more in depth as follows:

### Conditions of Everyday Living

Conditions of everyday living

This means that people with disabilities use the same places that other people of a similar age use for the same purpose. Children go to school. Adults work in businesses, service agencies, and factories. Recreational activities occur in movie theaters, restaurants, gyms, sports arenas, parks and other places in the community. Adults live in homes that are decorated according to their tastes. Most people live in one place and work or attend school somewhere else. It is out of sync when a person with disabilities has all training classes, structured therapies and recreation activities in the same building that serves as "home."

## Normal Rhythms of the Day, Week, Year

Normal Rhythms

Normal rhythms and patterns refer to the sequence of events experienced: in the day, in the week, in the year, and throughout the life cycle. Although some of us may have different schedules due to our jobs or life styles, we can picture a typical day. We get up in the morning and get dressed. We have breakfast typically around 7 or 8 a.m., lunch around noon, and dinner around 6 p.m. Most adults don't awaken before 6 a.m. or go to bed before 10 p.m.

This means that even if you have profound mental retardation, in the morning you get out of bed and get dressed. You don't stay in bed all day dressed in a gown. It means that you don't get up, get dressed, take a bath or have your meals at times dictated by staff convenience or shift changes. It means that if you are an adult, you don't have to go to bed at 8 p.m. because you have a mental age of three years and that's when three year olds go to bed.

Normal rhythms of week and year mean that people usually have weekend schedules that include chores, leisure, and religious activities. Holidays are celebrated at the same time and in ways similar to others in the community. July 4th is celebrated on July 4th, not on July 5th because the 4th was Sunday and there were not enough staff present to celebrate. Birthdays are celebrated individually and on the real birthday and not on the last Friday of the month for all people having birthdays that month.

Furthermore, few of us do the same types of activities through our lives. As children, we go to school. Later, we get a job. Eventually, we spend less time working. As we mature, we move from activities that are designed according to the wishes of our parents to more self-determined experiences.

## Normal Activities

Normal activities

Normal activities center around those things which are needed to maintain life and make it more enjoyable. For instance, after work, we go home and prepare our evening meals. We eat. We clean up. We do chores or engage in leisure activities until we are tired. Then we get ready for bed. When people with disabilities lack the skills to do any of these activities independently, they tend to be excluded from them. This leads to down time and boredom. It is very important to include people in these activities even if they can only partially participate and need a lot of support.

## Culturally Appropriate Teaching Strategies

Appropriate teaching strategies

The standard by which teaching methods must be judged is whether people at large would find the method typical and acceptable. For instance, teaching greeting through naturally occurring opportunities, modeling, and reinforcement is very acceptable in our culture. Practicing crossing the street in front of the residence for 30 minutes a day would look unusual and the skill probably would not transfer to crossing another street anyway. Many responses to unacceptable behavior, such as, physical restraints and take downs seem totally inappropriate to people in businesses, parks, and the community in general.

## Integrated Lifestyles

Integrated lifestyles

Finally, experiencing integrated lifestyles is the heart of normalization. This means living one's life with people without disabilities. On the job interactions with others are a part of the day (i.e., at breaks, before work, and after work). At home, interactions with neighbors and friends are common. In the community, resources should be used in the same way and time as other community members use them. Staff can assist in building these bridges for social interaction by creating typical routines, improving the social status of persons with disabilities, and helping community members to understand the similarities, as well as the differences between people with and without disabilities.

(Part of the above description of Normalization was adapted from An Introduction to Disabilities,1992, The University of Kansas, Kansas University Affiliated Program at Parsons.)

## Wolfensberger's Contribution

Wolfensberger's Contribution

Wolfensberger's contribution took Bank-Mikkelsen's normalized physical settings and added a social perspective to the concept, describing the effects of labeling and stigma. He observed how people were made to live in North American institutions. Why, he asked, were people collected in such large numbers, segregated and isolated? Why were they routinely abused and dehumanized? Why were basic human rights ignored and denied? What conditions and attitudes existed that allowed people to treat other people as non-human and not to care?

**Wolfensberger concluded that society had always identified certain groups as being outside the norms.** Such groups were called "deviant" because they had differences that were negatively valued by "normal" society. These various differences in appearance and behavior are called "stigmas."

Deviancy and stigmatization allows people to distance themselves from others. We de-value others, and the ultimate in de-valuing is to dehumanize..., not to truly believe that someone is a human being.

**When we truly see others as "not like us", not human, we can then accept and condone their brutalization.** We do so by focusing on the stigmatized **label**, instead of the people themselves. This is then exaggerated through their segregation from the "normal," congregation with "their own kind," deprivation and in some cases even willful extermination.

In the 1600's, for example, someone labeled "witch" was obviously not like everyone else. They were not seen as someone's brother or sister, son or daughter, and could be removed from the community, or put to death.

**People Interact With Their Environments**

Ecological Concept

People interact with their environments

It is important to understand that the concept of normalization is an **ecological** concept, that is, our first task is **not to try to "change" the person with the disability**, but rather to create living, learning, and work **environments** which are as normally as possible. It does not mean we are trying to make people "normal" (whatever that means). We don't deny the differences of people with disabilities, but we don't let those differences obscure their essential humanity either.

We know from studies done in psychology, sociology and other sciences that all behavior is purposeful. Often, people act in certain ways because of the environments in which they live. **"Environment" as used here means all of the things which we come into contact with, which influence us.** This can be:

- the physical environment (what we see, feel, hear, smell, taste, or touch), or
- the interaction (the bonding, affection, love, communication, and understanding) with other human beings.

**Normalization recognizes the power of the environment on people.**

*Objective 7:*

***List four misconceptions concerning the Principle of Normalization.***

Objective Seven

# MISCONCEPTIONS ABOUT NORMALIZATION

MISCONCEPTIONS ABOUT NORMALIZATION

**SHOW** ***Transparency 2.20 (Misconceptions)***

Transparency 2.20 (Misconceptions)

The Principle of Normalization has in the past often been misinterpreted. Some of these misconceptions are:

- **Normalization means making people "normal."** Normalization does **not** mean making people normal. An individual's behavior should not be forced to conform to a certain standard. This is regimentation, not normalization. Normalization **does** mean that there is an acceptance of people with their disabilities within "normal" society.

Making People Normal

- **Special services are inconsistent with the normalization principle, which supports dumping people from institutions into the community without support.** Normalization means that whatever supports are needed for an individual to lead as normal a life as possible should be given. An individual with developmental disabilities should receive the

No Supports

same services as any other member of that community.

Applies Only To Mild Disabilities

- **Normalization is an all or nothing concept, and applies only to people with mild disabilities.**
  The principle of Normalization applies to **all** people, including those with more severe disabilities. Only the range of support differs.

Scandinavian Concept

- **Normalization is a Scandinavian concept inapplicable elsewhere.**
  The principle of Normalization is neutral in regard to cultural values. The principle can be implemented in any other culture if the concepts of that culture's value system is taken into consideration.

Idealized and Impractical

- **Normalization is a humanistic concept, but idealized and impractical.**
  One of the **major benefits** of Normalization is its practicality and the way it provides concrete guidance for the treatment of individuals with developmental disabilities.

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## INSTRUCTOR QUESTIONS

**23. What is a practical application of the concepts we have learned?**

**24. What are "stigmas?"**

**25. What is meant by a "normal" environment?**

**26. Isolation from society results in what?**

27. Discuss the origin of the Principle of Normalization.

28. According to the Principle of Normalization, what is meant by the word "environment?"

According to the Principle of Normalization, what is meant by the word "environment?"

List and discuss common misconceptions concerning the Principle of Normalization.

## *Objective 8:*

***Discuss the importance of using the principle of normalization to improve public images for people with developmental disabilities as well as promote full social integration within the community.***

**Objective Eight**

# IMAGERY

IMAGERY

## BETTER IMAGES

BETTER IMAGES

### ACTIVITY **Cassette "Donny at the Bus Stop"**

Cassette:
"Donny At The
Bus Stop"

***Tell the participants to be aware of the clangers that are presented in this recording. Emphasize that while Garrison Keeler does use language that is Not People First, and while some of his imagery may not present the image of individuals with disabilities that we wish to convey, he does make the excellent point that "If we can return to our childhood when our minds were not cluttered with misconceptions and prejuidices, we will see that all people are just "people."***

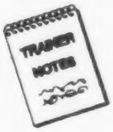
***Also, discuss the concept of images:***

- ***What were some of the inappropriate images presented by this recording?***
- ***How did the narrator's perception of the image presented by Donny change over the years? And, why?***
- ***How can the image a person presents affect the way he or she is perceived by society***
- ***How can this perception lead to the way an individual with developmental disabilities is treated?***

## PRESENT

Normalization includes ensuring the best possible image -- both self image and image in the eyes of the community -- for individuals with developmental disabilities.

**Normalization** means doing everything we can to integrate people who have developmental disabilities into everyday community life to enjoy all that we value for ourselves. As concerned persons, we must strive to eliminate negative images and associations and present people in positive and enhancing ways. We directly affect the individual and how others interpret that person.



***Arriving at an understanding of Nnormalization takes some study. It's a deceptively simple concept. This training by no means prepares you to become skilled in understanding and applying normalization. All participants are encouraged to attend normalization training opportunities as they become available.***

- ***It's also a complex, yet rewarding, experience to integrate its principles into our own subconscious. It's an awareness that opens our eyes.***

# INTERPERSONAL RELATIONS

INTERPERSONAL RELATIONS

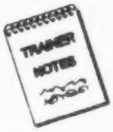
People are frequently at a loss as to how to act around those with disabilities. "What should I do?" "How can I know if I'm doing the right thing?" "If I look at the person, will s/he think I'm staring?" "If I don't look at the person, will s/he think I'm ignoring him or her?" These are typical reactions for people who have had little or no exposure to people with disabilities. As we get to know people with disabilities, our comfort level improves. We discover mutual interests and come to really realize that **people are people**.

Here are some of the more common mistakes we make in our dealings with people who have disabilities:

- A tendency to assume that the person with developmental disabilities is sad.
- A tendency to pity the person with developmental disabilities.
- Focusing on the disability so much that the person's other qualities are overlooked (the disability is only **one aspect of the whole person**).
- The unfortunate practice of treating people who have disabilities as if they were children.
- The avoidance of people with developmental disabilities.
- The tendency of trying to speak for people with disabilities instead of letting them speak for themselves.
- The failure of self discipline in avoiding use of derogatory humor.

# FULL SOCIAL INTEGRATION

FULL SOCIAL INTEGRATION



***When presenting this section, be sure to cover what is meant by "Social Integration."***

Most of us are able to get along with others because we learned how while growing up in typical towns and neighborhoods. Our first shopping trip to the corner store with a note from mother was an important lesson. So was our excitement in deciding what to buy with our allowance.

Each new skill built upon another because our environment provided significant opportunities to learn, imitate others, grow, and acquire social living skills.

**NORMALIZATION** means that people with developmental disabilities learn the skills necessary to function in society in the same way we do. They learn them by living and operating within the community. That means you learn to eat at a Mcdonald's by **eating** at a Mcdonald's, to work at WalMart by **working** at WalMart.

**SHOW** ***Transparency 2.21 (Social Integration).***

Transparency 2.21 (Social Integration)

***After presenting the section on fostering social integration, have the group to give examples of other things that they might think of that would also foster social integration.***

Here are a few hints about what we can do to foster full social integration:

- Encourage the mixing and interaction of people having developmental disabilities with ordinary people their own age in all areas of life.
- Demonstrate that integrated classes and job training are better growing and learning environments than segregated settings. Remember that "Pre" means "never":
  "Pre-Vocational"
  "Pre-Educational"
  "Pre-Living"
  These "getting-ready-to" phrases usually justify and continue segregation and dependency.
- Do your best to ensure that people with developmental disabilities dress, act, and appear in ways which don't make them appear odd.
- Be aware that when different groups with different needs are congregated together, we transfer erroneous or negative images from one group to the other. For example, when people with mental illness are mixed with people who have mental retardation, the tendency for the general public is to see them as one common group.

Many people have confused the problem of street people, which reflects a failure of deinstituionalization in the field of mental illness, with mental retardation which has done a fine job of moving people into the community with supports. This also tends to promote destructive competition for available staff resources and training opportunities.

- Always try to have people with disabilities together in numbers that will not overwhelm those around them. For example, don't herd people together in huge groups at churches or shopping malls or sporting events. One rule of thumb is to use what is call the "Principle of Natural Proportions." This means that since people with disabilities constitute, perhaps, three percent of the general population, they should be present at various activities in numbers not to exceed that percentage of the larger group.

We are all **interdependent** on one another. None of us is totally independent. Some people with disabilities will need almost no help to do real work, others may require a full-time job coach. Remember that our task is to provide the level of support needed to help inclusion happen, no more and no less.

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INSTRUCTOR QUESTIONS

**29. What is meant by the term, "Social Integration?"**

**30. Why will an environment that is artificial, manufactured, isolated, or markedly different from the norm frustrate the development of "normal" social living skills, or even encourage development of really "different" behaviors?**

**31. Discuss several ways you can foster full social integration.**

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**Normalization teaches us that the way to treat people with disabilities is like any other people.** You have your good days and your bad.

So do they.

You value your dignity and independence.

So do they.

You dislike being put down.

So do they.

## SHOW

**Transparency 2.22 (Tips).**

Transparency 2.22 (Tips)

## PRESENT

**Here are a few tips to keep in mind:**

- Where you live says a lot about who you are and how you are viewed by yourself or others. A home that looks "down and out" with a lawn that hasn't been mowed or paint peeling from the walls says the people who live there don't care and don't matter.
- A home should be in a residential neighborhood and should be an easy walk to shopping, recreation, and public transportation resources. It should be in the middle of things.
- Don't give a home an official name. You can't improve on the street address. Signs on the door only clang.
- Homes should fit in with their surrounding neighborhoods as much as possible.
- Living arrangements for people with developmental disabilities should be highly dispersed and not in zoning ghettos.
- A home should feel and look warm, be decorated thoughtfully and age appropriately.
- People with disabilities should be helped to dress in ways that are typical for their age. Adults should not wear childlike clothing. School-age children and teenagers should look like all other kids their own age.

People with disabilities are trying to overcome years of negative imagery. Their gains can be fragile. While most of our fellow Oklahomans are generally accepting, some are still carrying stereotypes and attitudes from the past.

*Objective 9:*
*Discuss three methods of recognizing and eliminating barriers to Normalization.*

# RECOGNIZING AND ELIMINATING BARRIERS TO NORMALIZATION

RECOGNIZING AND ELIMINATING BARRIERS

**NORMALIZATION** encourages us to require the full use of modern methods and technology in eliminating the physical and social obstacles that stand in the way of establishing normal environments for the people we serve. It encourages us to support men and women of compassion for leadership positions in our public and private organizations. And it encourages us to use the media in a way that is responsible -- not dehumanizing or stigmatizing.

**I. Methods of Recognizing Barriers**

**A. Awareness of Clangers**

**1. Eye**

**2. Ear**

**3. Mind**

**B. Appropriateness**

# AWARENESS OF CLANGERS

AWARENESS OF CLANGERS

***Introduce this section by asking the participants:***

- ***If they have any idea of what is meant by the term "Clangers." Ask them what picture the word summons up in their mind.***
- ***Write down their contributions on a flip chart for referral to later as you present the material on clangers.***
- ***Describe the three primary types of clangers. Discuss why they can lead to detrimental perceptions of individuals with developmental disabilities.***

## PRESENT

**A CLANGER is that instant recognition of oddity.**

In this training on Normalization, we decided that the best way to describe things that aren't normal was to help people understand and become sensitive to environments or behaviors that perpetuate labeling or stigmatization. Since each of us plays a role in helping create the environments in which people with developmental disabilities live, work, play, and learn, it's important to keep your antenna up and tuned to signals that say "label" or "stigma" or "obstacle." We call these signals CLANGERS. **A clanger is that instant recognition of oddity. It's a realization that something doesn't fit.** It might stick out like a sore thumb. Or, it might be very subtle.

We go through life noticing harmonies and oddities. We don't usually pay very much attention to things that seem in harmony. But we zero in quickly on things that seem odd. We develop and subconsciously use a pre-conceived list or set of conditions. And when we encounter something that is on that list, a lever is tripped and a bell goes **clang** in our heads.

It just happens.

***Write the following types of clangers on a flip chart and have the group give examples of what type clanger they believe each to be. Use this as an introduction to the material on clanger types.***

## PRESENT

Clangers can logically be divided into three types:

- **Eye Clangers**
- **Ear Clangers**
- **Mind Clangers**

## EYE CLANGERS

EYE CLANGERS

**Eye clangers are visual oddities.**

That's when you see something odd, mismatched or discomforting. Examples would be:

- a very official looking red fire bell on the front of a suburban home
- someone wearing outrageously mismatched clothes
- a barbed wire fence around a front yard
- a child-like dress on an adult woman.

## EAR CLANGERS

EAR CLANGERS

**An ear clanger is something that sounds strange or upsetting,** or something that alerts you to a mismatch.

It could be something said that doesn't make sense.

It could be someone using disrespectful labels such as racial slurs. Or when you hear someone using descriptions like "cripple," "mongoloid," "a C.P.," or "a severe."

***Give examples at this point of acronym clangers that you have heard commonly used.***

It could be a heavily biased phrase like "Anyone who voted for X is a complete idiot."

It could be hearing someone talk "baby talk" to an adult or it could be a loud dinner bell in a home.

It's anything you hear that makes your antenna rise an extra six inches.

## MIND CLANGERS

MIND CLANGERS

Mind clangers are things that jar your awareness. Something sets off a vibration in you that says there is something wrong.

It can be an occurrence that communicates ominousness or inappropriateness. Maybe you can't put your finger on exactly what it is but you know something is wrong or out-of-place. An example would be walking into a home and getting the feeling you're in an institution. Or it could be a realization that the adults in a "vocational training center" are actually doing "make work" or repetitious actions. (In one such center, clients put ballpoint pens together one day and take them apart the next.)

It could be the discovery of someone locked in isolation or it could be "bus trips to no-where."

It's anything that just doesn't **feel** right.

Naturally, not everyone is going to react in exactly the same way to things. What strikes me as being slightly odd may not trigger a clang in you. But every society has generally accepted norms, the violation of which will cause uneasiness in most people.

Remember that clangers are created by people who frequently are not aware that they are creating oddities. Even when they are aware of it, they may not be self conscious about it. People sometimes suspend their normal judgement when working with people who depend upon them. That's why we see people yelling loudly at an elderly person, assuming all people that age are hard of hearing.

## SHOW

***Video "Clangers"***

Video: "Clangers"

***As you show this video, discuss the clangers presented within it; what they are, what they represent, how they are perceived as oddities, etc., with the group. Ask for suggestions on other ways of accomplishing the acts or objects that are clangers in the presentation.***

- ***They can either find some "not so obvious" clangers in the presentation or think of some in their own environments.***
- ***You may also decide to break into small groups and have them list examples of clangers for presentation to the entire group.***
- ***Ask the group what will they do when they go back to work and see clangers in their environment. What do you do when you walk into a three bedroom ranch home and see a "time-out" room, or when you hear a professional talking "baby talk" to a 23-year-old individual? How will they handle these situations? List their ideas on the flip chart as they give them and use this to summarize the section on clangers and also Normalization.***

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# APPROPRIATENESS

## PRESENT

Inappropriate labels and symbols are clangers that focus negative attention on people with developmental disabilities. Diagnostic labels used to describe the person such as; "She is a "spastic" or "epileptic," or labels such as "unusual" or "abnormal." They can also be symbols that form negative images in your mind (such as dirty or torn clothes or a school bus taking adults on an outing). These are all inappropriate and potentially harmful.

Situations in which such people are seen doing things which are not appropriate to their age or to the culture in which they live also focus negative attention. They don't need stigmatizing labels, symbols and situations.

The things they need, as the Principle of Normalization shows us, are the same things everyone else needs. **They value what everyone else values.**

We don't mean by this that ordinary people are never seen in inappropriate ways. They are.

The problem is that negative images have a way of attaching very easily to people with disabilities. For instance, a rock star may wear a Mickey Mouse tee shirt to a formal dinner party. This is not appropriate to his age or to the occasion but because the star is highly valued in society, his behavior is seen as "cool" and no comments are made.

**Inappropriate labels and symbols are clangers that focus negative attention on people with developmental disabilities.**

If a person with mental retardation did the same thing, he would be seen as childish, ridiculous, and perhaps even repulsive. The rock star had a strong positive image to begin with, the person who has mental retardation did not.

### INSTRUCTOR QUESTIONS

**32. How can inappropriate methods of dress, behavior, and activities focus negative attention on people with developmental disabilities?**

**33. Discuss why a behavior might be inappropriate for an individual with developmental disabilities but not for someone else.**

## SUMMARY

SUMMARY

The image of a person with disabilities can be very fragile. Positive imagery must be promoted. People with developmental disabilities must first become comfortable with their own self-worth. Attitudes, both of the individual and his family as well as society must change. And although this may be a time-consuming and frustrating task at times, we will eventually reap a harvest of valuable individuals who recognize their own worth, their own talents, skills and capabilities, and whom society recognizes and cherishes as important, contributing members.

# EXAM

## Module Two

Date________________ Name__________________________

# Changing Times

## MODULE EXAM

______1. **The historical role perception in which people with disabilities were perceived to be little more than animals or vegetable is an example of**
   a. Object of Pity perception.
   b. Object of Charity perception.
   c. Subhuman Organism perception.
   d. Eternal Child perception.

______2. **Belief that God will reward us if we are kind to people with developmental disabilities is an example of the**
   a. "Holy Innocents" perception.
   b. "Eternal Child" perception.
   c. "Object of Charity" perception.
   d. "Sick Person" perception.

______3. **The belief that people with disabilities must be cared for because they will never be able to care for themselves is an example of**
   a. "People With Developmental Disabilities Should Have Special Environments" misconception.
   b. "A Person Can Function To The Extent of His/Her Mental Age or IQ" misconception.
   c. "A Life Of Complete Dependency" misconception.
   d. "All People With Mental Retardation Act Alike" misconception.

______4. **Parents had been told by professionals that their children would never be able to care for themselves**
   a. but they researched ways to help their children realize their full potentials.
   b. so they often put their children in congregate care facilities.
   c. but they found other professionals who were willing to work with their children.
   d. all of the above.

______5. **The role of the Arc has evolved to**
   a. be an active plaintiff in federal and state court cases involving the rights of citizens with developmental disabilities.
   b. improve the educational, residential, and support services for individuals with developmental disabilities.
   c. be instrumental in leading the movement for institutional reform and the creation of new community alternatives.
   d. all of the above.

______6. **Media exposes about conditions in institutions and federal lawsuits resulted in**
   a. deinstitutionalization.
   b. disillusionment.
   c. congregation.
   d. desegregationalism.

______7. **The Homeward Bound vs. The Hissom Memorial Center lawsuit resulted in**
   a. resulted in an improvement of institutional facilities as a principal option for individuals with developmental disabilities.
   b. a shift away from institutions and toward normal community lifestyles for people with developmental disabilities.
   c. Both a and b.
   d. Neither a or b.

______8. **The Oklahoma parent experience**
   a. was the same as that of other parents across the nation.
   b. resulted in congregate care facilities becoming the main residential option in the state.
   c. was a unique event that was unparalleled in our nation's history.
   d. did not have any major or long-lasting consequences concerning the lives of individuals with developmental disabilities.

______9. **Congregate care facilities**
   a. surround people with appropriate role models.
   b. apply real skills in real settings.
   c. do not work because people with disabilities should not be relegated to special environments.
   d. are an example of "bigger is better."

______10. **Segregation is**
   a. the separation of the individual from society.
   b. the inclusion of an individual into society.
   c. the integration of an individual into society.
   d. none of the above.

______11. **Inclusion is**

_______**11. Inclusion is**
a. the presence of an individual within society.
b. the participation of an individual within society.
c. the absence of an individual from society.
d. the presence and full participation of an individual within society.

_______**12. Lack of contact of individuals with developmental disabilities with other people in society results in a**
a. lack of knowledge about people with disabilities.
b. fear of the unknown things people with disabilities may do.
c. justification for distancing society away from people with developmental disabilities.
d. all of the above.

_______**13. The Rehabilitation Act of 1973**
a. was the first civil rights law to guarantee equal opportunity for individuals with disabilities.
b. guaranteed a free and appropriate education.
c. established an early intervention program for young children.
d. established deadlines for equal opportunity and equal access requirements.

_______**14. The Americans With Disabilities Act of 1990**
a. was the first civil rights law to guarantee equal opportunity for individuals with disabilities.
b. guaranteed a free and appropriate education.
c. established an early intervention program for young children.
d. established deadlines for equal opportunity and equal access requirements.

_______**15. The term "Choice" is defined as**
a. things to which individuals have just claim.
b. something that indicates or implies a decision an individual must make based on the facts he or she has accumulated.
c. a behavior that cannot infringe upon the rights of another individual.
d. unlimited exercise of the rights guaranteed to all individuals.

_______**16. When all information and options on a subject is presented before an individual, he or she can then**
a. make an informed choice.
b. have an unlimited range of choices.
c. develop responsibility concerning choices.
d. a and c.
e. all of the above.

_______17. **Abuse is defined as**
- a. the unjust or improper use of the personal resources of another person.
- b. the intentional infliction of physical pain, injury, mental anguish, or deprivation of food, clothing, shelter, or medical care.
- c. willful omission rather than commission of an act.
- d. causing an unintentional injury to an individual.

_______18. **Subjecting an individual to an atmosphere in which the person does not feel secure, wanted, or worthy is**
- a. exploitation.
- b. neglect.
- c. emotional abuse.
- d. physical abuse.

_______19. **Exploitation**
- a. the unjust or improper use of the personal resources of another person.
- b. the intentional infliction of physical pain, injury, mental anguish, or deprivation of food, clothing, shelter, or medical care.
- c. willful omission rather than commission of an act.
- d. participation of a caretaker in acts of ridicule toward another individual.

_______20. **The failure to provide protection for a person who is unable to protect his or her own interests is called.**
- a. exploitation.
- b. neglect.
- c. emotional abuse.
- d. physical abuse.

_______21. **Any person who knowingly and willfully fails to promptly report any abuse, neglect, or exploitation shall, upon conviction, be guilty of**
- a. felony.
- b. violation of a departmental policy.
- c. misdemeanor.
- d. none of the above.

_______22. **Mistreatment may be prevented by**
- a. treating all people with respect and dignity.
- b. becoming preoccupied with orderliness.
- c. establishing control over an individual early in your relationship.
- d. never admitting that you have made a mistake.

_______**23.** **All behavior is**
a. a form of communication.
b. purposeful.
c. is in response to either internal or external stimulus.
d. all of the above.
e. a and b.

_______**24.** **Oklahoma is committed to eliminating**
a. non-aversive methods of working with people with disabilities.
b. aversive methods of behavior modification.
c. situations that may provoke the use of non-aversive methods.
d. none of the above.

_______**25.** **A practical method of applying the abstract concept of values to the real world is**
a. teaching skills in artificial settings.
b. by establishing special environments.
c. the Principle of Normalization.
d. Behavior Modification.

_______**26.** **The Principle of Normalization**
a. does not try to change the person with the disability but rather to create living, learning, and work environments which are as normal as possible.
b. suggests that people do not act in certain ways because of the environment they live in.
c. suggests that everyone is independent of one another.
d. creates environments that do not allow for interaction with the people who live in them.

_______**27.** **The longer people in society are around individuals with disabilities, the more**
a. they justify segregation and congregation.
b. their comfort levels improve.
c. they discover mutual interests.
d. a and b.
e. b and c.
f. all of the above.

_______**28.** **An environment that is artificial, isolated, or markedly different from normal environments will**
a. frustrate the development of "normal" social living skills.
b. encourage the development of "normal" social living skills.
c. encourage segregation and foster congregation.
d. frustrate social labeling and stigmatization.

_______**29.** **Full social integration can be helped by**

_______**29.** **Full social integration can be helped by**
a. making sure homes for individuals with disabilities look cared for and inviting.
b. giving the residence a name that identifies the people who live there.
c. organizing large group outings for individuals with developmental disabilities.
d. encouraging the mixing of individuals with mental illness with individuals with mental retardation.

_______**30.** **Appropriateness is important when working with people with disabilities because**
a. the use of inappropriate activities or things can promote poor public images of people with developmental disabilities.
b. people value what everyone else values.
c. people with disabilities do not have strong public images to begin with.
d. all of the above

_______**31.** **An instant recognition of oddity is called a**
a. barrier.
b. clanger.
c. injustice.
d. none of the above.

_______**32.** **Visual oddities (when you see something odd, mismatched or discomforting) are called**
a. ear clangers.
b. mind clangers.
c. eye clangers.
d. visual barriers.

_______**33.** **Things in that jar an person's awareness are called**
a. ear clangers.
b. mind clangers.
c. eye clangers.
d. visual barriers.

_______**34.** **An example of an ear clanger is the following phrase**
a. "that retard"
b. "epileptic"
c. "anybody who would do *that* is a real idiot"
d. all of the above

______35. **Clangers are often created by people who frequently**

a. do not know they are creating oddities.
b. consciously try to find terms that are inappropriate.
c. suspend their normal judgement when working with people with disabilities.
d. a and c.
e. all of the above.

## EXAM ANSWERS -- MODULE THREE

1. C
2. A
3. C
4. D
5. D
6. B
7. C
8. A
9. C
10. A
11. D
12. D
13. A
14. D
15. B
16. B
17. B
18. B
19. A
20. B
21. C
22. A
23. D
24. B
25. C
26. A
27. E
28. A
29. A
30. D
31. B
32. C
33. B
34. D
35. A

# HANDOUTS

## Module Two

The Tulsa Tribune

# Wasting away
## in Oklahoma

Special report

Oklahoma is scrambling to overhaul its system of care for the mentally retarded for the first time in decades.

But change is slow for the 90,000 retarded Oklahomans neglected by an archaic system . . .

**Reprint of a series published Oct. 1-10, 1984**

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2C

An afternoon at Pauls Valley State School for the Mentally Retarded.

# State schools: a one-way door

*"The striking feature of the residents I observed - that they simply do not belong in nor can they be helped in this facility. . . .*

*It is a tragedy to see such high functioning adults wasting away in this program."*

**— From a June 1982 U.S. Justice Department report on Enid State School**

TUCKED AWAY in Oklahoma's three institutions for the mentally retarded are hundreds of people who don't belong there.

Oklahoma's new welfare regime is scrambling to overhaul outmoded programs that offer help only to those in institutions, isolated from families and communities.

It is a move experts say is long overdue.

At stake is the future for about 90,000 mentally retarded Oklahomans.

**Institutions at Sand Springs, Pauls Valley and Enid are home to 1,600; most of the others live with their families.**

Many desperately need help Oklahoma has never provided because the state's money has been tied up in institutional care, which experts say is more expensive and often unnecessary.

In a recent survey by a national accreditation society for mental retardation programs, Oklahoma ranked 50th in the nation — dead last — in providing care for the retarded outside of institutions.

**A PLAN DEVELOPED** a year ago by the Department of Human Services (DHS) calls for hundreds to be moved out of the institutions.

The problem is that alternatives to institutions simply do not exist in Oklahoma.

Outside of a handful of private programs that have few vacancies, about the only place a mentally retarded person can live is with family or in a nursing home designed for the elderly.

**DHS officials — under threat of a cutoff of federal funds — say they are creating alternatives from specialized foster care, babysitting and adult day care to group homes and nursing homes with programs geared to them.**

Institutions will remain an option, but officials say the kind of care they offer will change.

Most residents will be profoundly retarded and multiply handicapped. The mildly and moderately retarded who do come to the institution will receive short-term training rather than long-term custodial care.

**FOR NEARLY 10 YEARS** the federal government, which holds the purse strings to Medicaid, has criticized the state's institutions. Those federal funds pick up 55 percent of the tab.

However, political observers say former Oklahoma Welfare Director Lloyd Rader kept an iron grip on operation of the schools and fought "tooth and toenail" every attempt to change them.

"The feds just never went to the mat with him," said state Sen. Bernest Cain, D-Oklahoma City, a legislator whose subcommittee handled funding for the schools.

"He had a lot of friends in Washington."

Rader retired two years ago.

**Both interim DHS Director Henry Bellmon and current Director Robert Fulton made changes in the state's programs for the mentally retarded a top priority.**

In July, federal officials threatened to cut off $25 million a year to the three institutions if a plan is not submitted to correct problems.

The plan has been submitted and is awaiting formal approval by the government.

The federal government had been making similar threats for years.

This time, DHS officials did not argue.

"We just took all the comments and decided it was better not to spend time arguing over the validity of them but rather to work on a plan to correct problems," said Jean Cooper, director of mental retardation services for DHS.

**OKLAHOMA** has provided a one-way door for the mentally retarded.

A lack of community programs has led to the retarded being placed in an institution and also prevented many of them from being released.

"Fifty percent or more of the residents are not in need of and do not benefit from being in" the facilities, reported a physician who investigated schools at Pauls Valley and Enid for the U.S. Justice Department in 1982.

Judges, lawyers, physicians and state officials "ignored" the law and placed people in the institutions because they had nowhere else to put them, said Steven Thomas, who resigned as superintendent at Pauls Valley State School last month.

**"They've put some people here — we've violated every right they have," Thomas said.**

These people are not mentally ill or "crazy." They cannot be "cured."

Birth defects or injury during their developing years causes them to function at an intelligence

See INSTITUTIONS, page 4.

## About the series

the summer of 1984 a dozen employ- of an Oklahoma state school for the mentally retarded were suspended after a 7-year-old boy allegedly was abused at the school.

As they looked into the story, editors and reporters at the Tulsa Tribune found the problems in Oklahoma's system of care for the mentally retarded reached far beyond one little boy to encompass the lives of Oklahoma's 90,000 retarded citizens.

Reporters Susan Witt and Joyce Peterson and photographer Eli Reichman spent three months examining the state's system and talking with those it affects.

News Break

Leader
Wednesday, July 3, 1991

A-3

# Removed from 'shelter,' Hissom client feels free

The first encounter staff w[illegible] in the supported employment project sponsored by the Department of Human Service had with Susie Meech was in a sheltered workshop where the perpetually happy young woman had been employed in a sheltered, non-competitive job for five years. She had also worked at a flower nursery at The Hissom Memorial Center but there had been no history of work in the community for wages.

Now, after 2½ years, this 27-year-old woman has her own apartment, job and busy social calendar. Meech is also a person with a developmental disability, Down Syndrome.

The about-face in Meech's employment career started when she was assigned a job coach through a Department of Human Services employment program. Dorsey Taylor-Zinga began working with Meech. She located a job Meech was interested in, educated the employers and co-workers about the developmentally disabled and [illegible] worked the job personally [illegible] learn all the job entailed.

When it was established the job would be an appropriate job match, Meech went to work. The employer, McDonald's, has been a leader in hiring individuals with developmental disabilities.

Meech's work schedule was Friday, Saturday and Sunday from 5 a.m. until 12 noon, making salads and biscuits. As Zinga's alarm went off at 3 a.m. on those days, she would groan, dress and stumble out the door. But not Meech! When her alarm rang, she was ready and anxious to don her work uniform which she had washed and ironed the night before. By 4:30 a.m., she had made her bed, bathed, and styled her hair. At 4:35 a.m. she was in front of the house with purse in hand, waiting for her job coach.

Susie Meech goes to work with briefcase.

Zinga had worked out a time and training schedule which allowed for some of the obstacles Meech might, and did, encounter. A task analysis was [illegible]ted to break down each job task into do-able smaller parts to help the worker understand what is required to get that particular task completed.

Job tasks were learned through verbal instructions, instructional repetition, and modeling techniques. Zinga soon learned Meech's main problem was the rate (speed) at which certain tasks were being done.

After trying several methods to speed up Meech's production, Zinga finally found the answer in music and rythm. Using a 'rap' form of training, she found rhythm and consistent beat trigered an internal cue for Meech to work by.

After five months of intensive training, Meech was able to work completely on her own. Meech held her job for two years before deciding she would like to have a job where she could talk to others who had developmental disabilities.

In May of this year, Transitional Living, Inc., Tulsa, hired Meech as client communication coordinator/client social director and part time office hostess. Her job duties include coordinating special events, setting up meetings and meeting rooms and communicating all of the social and recreational events that are available in the area to the clients.

Zinga said she was flooded with emotions at Meech's employment success. "I am so proud of her but I also know our relationship will never be the same again ... Susie no long needs me."

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# Consent Decree Signed in Hissom Case; Review Panel Established

On December 4, U.S. District Judge James Ellison, of the Northern District Court of Oklahoma approved a consent decree that will substitute for a 1987 "court plan and order of deinstitutionalization" in the case of *Homeward Bound v. the Hissom Memorial Center*. The consent decree establishes a framework for a community service system that will serve as an alternative to institutional care for current residents of Hissom (as well as some former residents).

**Background.** The suit was initially filed on May 2, 1985 on behalf of the Hissom class, to obtain relief from alleged unlawful treatment by the Oklahoma Department of Human Services. The class consists of the "focus class," which is made up of all people who currently reside at Hissom, or who resided there prior to May 2, 1985 and the "balance class," including all other former residents. After several interim orders related to services provided at Hissom, the "court plan and order of deinstitutionalization" became effective on October 21, 1987. The court appointed a monitor in May, 1988 to facilitate the implementation of the decree. In addition, an appeal filed by the State DHS is still pending in the U.S. Court of Appeals for the Tenth Circuit.

In May, 1989, the Department was directed by the court to "devote substantial resources" to the development of plans to afford present and former Hissom residents "quality habilitative care in community settings." This directive emerged, in part, from the fact that both parties in the litigation "have now had almost two years of experience under the 1987 court order, and based on that experience, they have a much better understanding of the difficulties involved in the transition from a system of care ... based primarily on institutional treatment to a system based primarily on community services, of the amount of time required to effect transitions of [Hissom residents] to community settings, of the resources that are available to support a service delivery system based primarily on community service, and of the costs involved in such a system."

As a result of this experience, according to the consent decree, the plaintiffs and the defendants now wish to terminate the litigation concerning care and treatment of the class, including the pending appeal, and move to an agreed-upon structure for carrying out a service program that will provide appropriate relief for the class, in a manner that is consistent with the 1987 order. Thus, the December 4 consent decree supersedes the 1987 order and all subsequent court orders.

**Provisions of the Consent Decree.** The consent decree consists of six sections, each of which is divided into a series of provisions. These sections are summarized in the succeeding sections of this article.

*Provisions Related to the "Focus Class."* The central goal of both the court order and the consent decree is to transfer all Hissom residents (and the approximately 100 other individuals who resided in Hissom in May, 1985 and subsequently were discharged) to appropriate community settings or to provide an appropriate array of services and supports for them in accordance with their individualized habilitation plans. No new admissions will be made to Hissom, and the target date for completion of outplacements in October 1, 1993. The range of residential options will include independent living, natural homes, adult companion programs, shared living arrangements, foster homes, supported living arrangements, small group homes and small ICF/MRs.

According to the placement process outlined in the consent decree, individual habilitation plans will be developed by interdisciplinary teams, reviewed and approved by DHS, and submitted to a review panel for certification recommendation. The review panel must recommend either approval, or that a conference or hearing be held; the client and his or her representative will have an opportunity to participate in a conference or hearing. Priority for discharge will be given to class members who request placement in community settings.

All focus class members will have a case manager on or before June 30, 1990; case managers will be qualified mental retardation professionals. During the transition process, there will be one case manager for every ten clients; when class members have been in their community placements for one year, and are considered stabilised in such settings, the ratio will be one case manager to twenty clients.

*Provisions Related to the "Balance Class."* The decree categorizes balance class members into those residing in: (a) a private ICF/MR; (b) an institutional setting other than a private ICF/MR; or (c) community settings. For those in private ICF/MRs or institutional settings other than private ICF/MRs, IHPs will be prepared by Octob 1, 1990. They will be offered the oppo tunity to transfer to community settings. F those already in community settings, cas managers will be assigned by October 1993.

*Provisions Related to the Entire Class.* Th role of parents/families is outlined in th agreement; parents/guardians will be mer bers of the IDT for their family member, ar involved in all team decisions. Clients ar families will have the right to select servic providers from a State-approved list of pr viders. A system of safeguards is outline in the decree, and DHS is directed to secu technical assistance from the outside assist in the development and implemer tation of a quality assurance program, ir cluding compliance with ACDD standard The facility will be maintained and operate as an ICF/MR, in compliance with Sta and federal requirements, during the enti period covered by the consent decree. DH agreed to prepare a phase down plan f Hissom, to be submitted to the court March 5, 1990.

*Provisions Related to Oversight and Dispu Resolution.* The consent decree includes detailed section on oversight and dispu resolution, outlining a process for inform resolution as a preferred option. The cou establishes in the decree, the Homewar Bound Review Panel, a panel of three ir dividuals who will be assigned primary r sponsibility for assisting the court and th parties in the suit to carry out the decre This panel will replace the Court Monitc whose role will be terminated.

The panel is authorized to hire up to thre staff members with experience in ment retardation and two support staff member

*Financial Provisions.* The agreeme specifies that it does not require the expe diture of more funds on an average, p capita basis to maintain and serve clients the community than the amount require to serve them at Hissom. This standard a plies on an aggregate (not case-by-cas basis.

*Miscellaneous Provisions.* A series of adc tional provisions governing access records, termination of the decree, defir tions and legal provisions are included the final section of the consent decree. Th decree will be terminated three months aft the last client is transferred out of Hissor

(reprinted from Newsletter of the National Asso. of State Mental Retardation Program Directors, Inc.)

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# *The Enlightening Principle of Normalization*

Normalization means. . .*a normal rhythm of the day.*
You get out of bed in the morning, even if you are profoundly retarded and physically handicapped;
you get dressed,
and leave the house for school or work, you don't stay home;
in the morning you anticipate events,
in the evening you think back on what you have accomplished;
the day is not a monotonous 24 hours with every minute endless.
You eat at normal times of the day and in a normal fashion;
not just with a spoon, unless you are an infant;
not in bed, but at a table;
not early in the afternoon for the convenience of the staff.

Normalization means...*a normal rhythm of the week.*
You live one place,
go to work in another,
and participate in leisure activities in yet another.
You anticipate leisure activities on weekends,
and look forward to getting back to school or work on Monday.

Normalization means...*a normal rhythm of the year.*
A vacation to break the routines of the year.
Seasonal changes bring with them a variety of types of food, work, cultural events, sports, leisure activities.
Just think...we thrive on these seasonal changes.

Normalization means...*normal developmental experiences of the life cycle.*
In childhood, children, but not adults, go to summer camps.
In adolescence one is interested in grooming, hairstyles, music, boyfriends and girlfriends.
In adulthood, life is filled with work and responsibilities.
In old age, one has memories to look back on, and can enjoy the wisdom of experience.

Normalization means...*having a range of choices, wishes, and desires respected and considered.*
Adults have the freedom to decide where they would like to live,
what kind of job they would like to have, and can best perform.
Whether they would prefer to go bowling with a group,
instead of staying home to watch television.

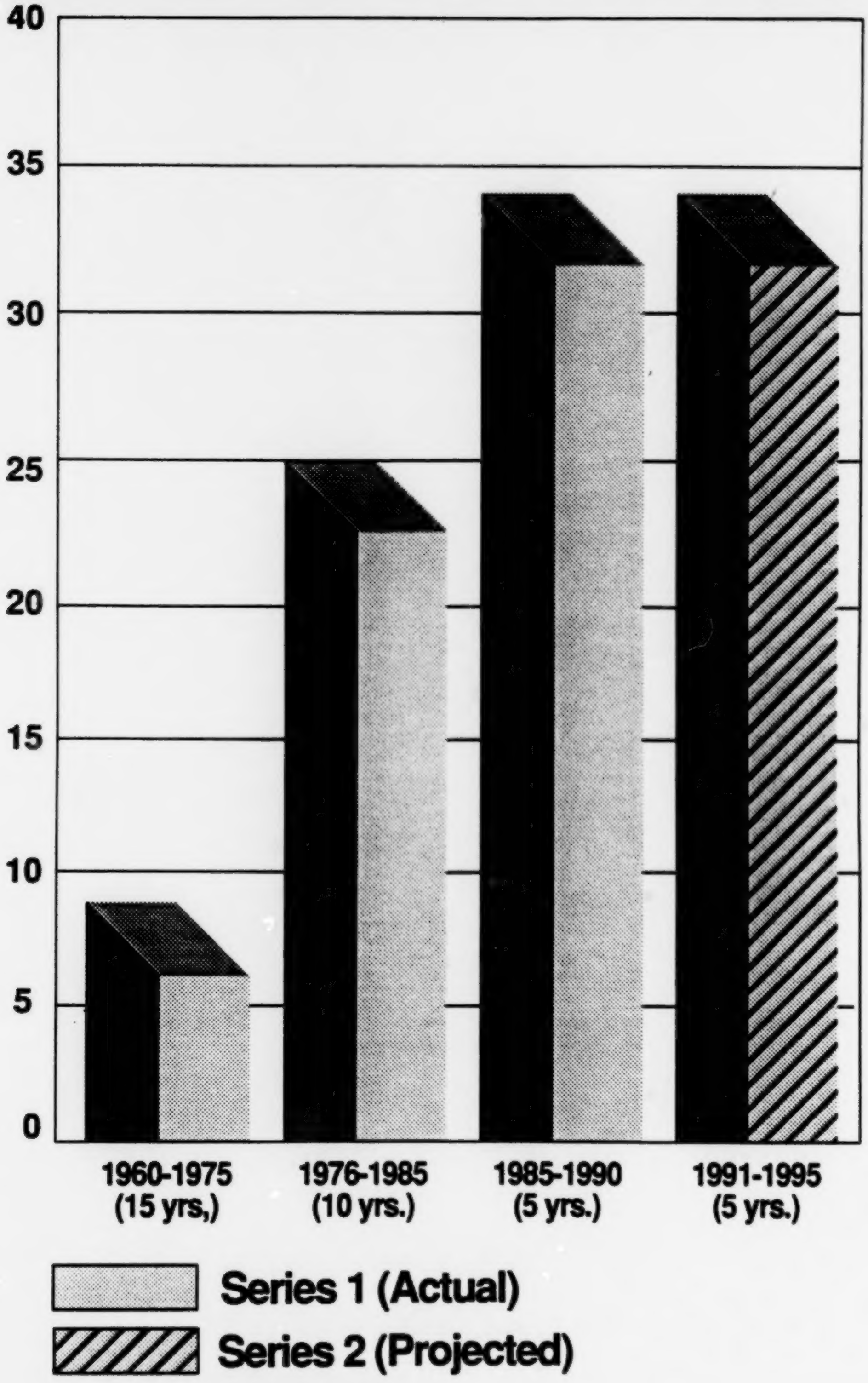
Normalization means...*living in a world made of two sexes.*
Children and adults both develop relationships with members of the opposite sex.
Teenagers become interested in having boyfriends and girlfriends.
And adults may fall in love, and decide to marry.

Normalization means...*the right to normal economic standards.*

All of us have basic financial privileges and responsibilities,
are able to take advantage of compensatory economic security means, such as child allowances, old age pensions, and minimum wage regulations.
We should have money to decide how to spend; on personal luxuries or necessities.

Normalization means...*living in normal housing in a normal neighborhood.*
Not in a large facility with 20, 50, 100 other people because you are retarded.
And not isolated from the rest of the community.
Normal locations and normal size homes will give residents better opportunities for successful integration with their communities.

## U.S. Closures & Projected Closures of State Institutions – Persons with MR/DD



*Population: 220,000 Peak*
*65,000 Currently*

# REPORTING MISTREATMENT

## To make a report call:

- **the local DHS office;**
- **or the local office of the District Attorney;**
- **the DHS Abuse Hotline**

**at**

**1-800-522-3511**

You may also call the Office of Client Advocacy at

**1-800-522-8014 or 1-405-521-3491**

## Content of Reports

**All reports of abuse and neglect should include the following information:**

- **The name and address of the individual being abused or neglected;**
- **The name and address of the caretaker, if any;**
- **A description of the situation.**

# SUPPLEMENTAL INFORMATION AND ACTIVITIES

## Module Two

# The Parent Experience

# HOLLAND...

## NOT ITALY.

DEAR ABBY: Your column several months ago about Down's syndrome children had a profound effect on me. I especially appreciated the piece "Welcome to Holland." As a mother who has raised three special-needs children —now adults — I resented that awesome responsibility to the point where I could no longer enjoy life. I wanted to be able to do the things with my husband that any other "empty nest," middle-aged couple did. Instead, I was cast in the role of a mother with adolescent-like children. It wasn't fair.

Their demands are small, but their love is enormous. These are the windmills, the tulips and the Rembrandts of Holland. I won't find them in Italy. Thank you, Abby, for sharing that wonderful piece with your readers.

**Jeanne Starr**, Mississippi

DEAR JEANNE: I appreciate your kind words about the piece, and because October is Down's Syndrome Awareness Month, I've been asked to run it annually. The author is Emily Pearl Kingsley.

For information on Down's syndrome and support groups in your state, please contact the National Down's Syndrome Congress at this toll-free phone: (800) 232-6372.

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability — to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this ...

When you're going to have a baby, it's like planning a fabulous vacation trip — to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Universal Press Syndicate

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THE BOSTON GLOBE • FRIDAY, JANUARY 1, 1993

# Belchertown padlock marks shift in care era for retarded

By Jeff Donn
ASSOCIATED PRESS

BELCHERTOWN – Former residents, their families, and officials yesterday marked the closing of the Belchertown State School, the focus of a 20-year battle over conditions in state institutions for the retarded.

State officials who supervise care of the retarded joined in padlocking the administration building in a symbolic gesture.

"The horrible conditions of the past can be contrasted with today's small, family-like settings in the community," said Philip Campbell, the state's commissioner of mental retardation. He argued that the legal struggle over Belchertown has led to improvements in the system.

But Benjamin Ricci, chairman of the Amherst-based Advocacy Network, urged continued court supervision of state care in community settings.

"This is less a matter of closing and celebration than a change of address as well as a clear and strong reminder to Gov. William Weld of the commonwealth's obligation to provide quality lifetime services," he said.

The last three of the school's 270 clients were moved to smaller community homes Dec. 17. The 70-year-old institution of about 40 buildings in rural Belchertown is the first to be closed in the state.

But state officials have pledged to close four other institutions for the retarded as part of a court-supervised agreement: Monson State School, Walter Fernald State School in Waltham, Wrentham State School, and Paul Dever State School in Taunton. Closing dates have not been set, said Gerald Ryan, a spokesman for the Department of Mental Retardation.

The Belchertown institution was once the most notorious for its conditions.

"When I first came here, I thought I'd commit suicide, because I never saw bars on the windows like here. But I'm free now," said Patricia Summers, 57. The 25-year resident now lives in a Greenfield apartment with her husband.

Ruth Sienkiewicz-Mercer, who wrote a book called "I Raise My Eyes to Say 'Yes'" about her 16 years at Belchertown, spoke to about 200 participants at the ceremony through a synthetic voice computer. She has cerebral palsy that confines her to a wheelchair. "As I think back on the years I lived here, I feel both sad and angry," she said. "I am angry that people in those days felt like the only way to deal with people with disabilities is to put them in institutions."

Ricci opened the fight over Belchertown with a 1972 lawsuit on behalf of his son, Robert Simpson, who lived there, as well as other residents.

The suit prompted Judge Joseph Tauro of US District Court in Boston to visit the institution. He reported seeing a girl drinking from a toilet and half-naked people rolling in excrement.

State officials agreed 15 years ago to court oversight of their efforts to move residents into private homes and group residences. They have been trying without success in recent months to end that supervision.

Ricci said it took him 20 years to demonstrate that the state was failing to provide good care to retarded clients.

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## Conclusion

Normalization sometimes has been criticized for failing to "cure" people of their retardation, for failing to produce perfect programs and life situations. Of course it doesn't![8] Normalization is a necessary condition, providing a framework with guidelines and major implications for many specific actions and programs. But it makes no pretense of answering all possible questions. Even within a normalization context, good programs, capable and interested staff and volunteers, supportive and courageous parents and friends are needed. Normalization will not solve all problems, yet understanding and implementation of the principle will provide a good start.

The principle of normalization has been misunderstood for too long. A proper understanding of what it means can go a long way towards improving services and life conditions of handicapped people. ●

FOOTNOTES

[1] Bengt Nirje. "The Normalization Principle and its Human Management Implications," in R. Kugel and W. Wolfensberger (Eds.) *Changing Patterns in Residential Services for the Mentally Retarded* (Washington, D.C.: President's Committee on Mental Retardation, 1969).

[2] Bengt Nirje. "The Normalization Principle," in R. Kugel and A. Shearer (Eds.) *Changing Patterns in Residential Services for the Mentally Retarded* (Rev. ed.) (Washington: President's Committee on Mental Retardation, 1976). Reprinted in R. Flynn and K.E. Nitsch (Eds.) *Normalization, Social Integration, and Community Services* (Baltimore: University Park Press, 1980). This book is an excellent source for other statements of normalization and its implications. Note that this definition is different from both Wolf Wolfensberger's original definition (in *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation, 1972) and his revised version (in "The Definition of Normalization: Update, Problems, Disagreements, and Misunderstandings" in Flynn and Nitsch). These differences and their implications will be addressed in my Congress paper with Nirje (Ibid).

[3] Niels E. Bank-Mikkelsen. "The Principle of Normalization," in Børge Nielsen (Ed.) *Flash #2 on the Danish National Service for the Mentally Retarded* (Copenhagen: Personal Training School, April 1976), pp. 27–28.

[4] Wolfensberger, op. cit. does speak of normalizing people, and in this respect is in divergence with Nirje, Bank-Mikkelsen, and with me. This terminology has connotations of dictating "acceptable" behaviour (e.g. appropriate hairstyles) for handicapped people in ways quite different than for others in society. Wolfensberger, 1980 (op. cit.), however, has indicated clearly that he does not mean that a person should be fitted to the statistical norm of society, and has described this view as a "naive and invalid" interpretation of the normalization principle (p. 80).

[5] Nirje, 1976, op. cit.

[6] Gunnar Dybwad. "The Re-Discovery of the Family," *Mental Retardation*, Vo. 32, No. 1, Winter 1982, pp. 18–30.

[7] E.g. see Marc Gold. "Stimulus Factors in Skill Training of Retarded Adolescents on a Complex Assembly Task: Acquisition, Transfer and Retention," *American Journal on Mental Deficiency*, Vol. 76, 1972, pp. 517-526.

[8] In addition, as Wolfensberger has indicated (1980, op. cit.), the normalization label has been attached falsely to many poor programs (e.g. cases of dumping people into inadequate, pitiful community facilities, as discussed under Misconception 2). In cases such as these, normalization has been blamed incorrectly for the very real deficiencies of these programs.

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*Burt Perrin is President of the Advocacy Resource Centre for the Handicapped (located in Toronto), and also is a co-ordinator of program evaluation for the Ontario Ministry of Tourism and Recreation.*

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# Misconceptions about the principle of normalization

*Burt Perrin*

While the principle of normalization evolved in Scandinavia during the 1960s, with primary credit going to Niels Bank-Mikkelsen, the first systematic statement of the principle in any language, at least in print, was provided by Bengt Nirje in 1969.[1] In a very short time since, normalization quickly became one of the most influential and widely quoted concepts internationally in mental retardation, and has played a major role in the movement, however slow, towards community living. The principle has major implications regarding the way handicapped people are viewed and the programs developed for them.

Yet the principle of normalization has been widely misunderstood, both by many of its advocates as well as by its critics. In some cases it has been misinterpreted so perversely as to produce implications and programs directly opposite to what is meant by the principle! The purpose of this article is to briefly identify and discuss a few of the more common misconceptions.

Quickly, what is the normalization principle? As defined by Nirje:

> "The normalization principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society."[2]

Bank-Mikkelsen describes normalization as the acceptance of mentally handicapped persons *with* their handicap, offering them the same conditions as are offered to other citizens, inclusive of treatment, education, and training needed to provide for optimal development.[3]

### Misconception 1: "Normalization means making people normal"

Probably the most common misinterpretation of the principle of normalization is the mistaken belief that it means mentally handicapped people must be expected to, indeed be forced to act "normal", to conform in all respects to society's statistical norms for all dimensions of behaviour. Normalization frequently has been confused with normalcy.

Normalization does *not* mean normalcy, it does *not* mean that people should be normalized,[4] it does *not* mean that anyone's behaviour should be forced to conform to any particular standard (e.g. what 51 percent of one's neighbours do), it does *not* mean that mentally handicapped persons are expected to be made normal or to act like other

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*Many of the ideas expressed in this paper have arisen out of discussions with Bengt Nirje, and the author wishes to acknowledge his assistance.*

people. It *does* mean that opportunities and support should be provided to permit a lifestyle similar in nature to that of other members of society, including the same opportunities for individual variation and choice. Normalization means the acceptance of persons *with* their handicap within "normal" society, with the same rights, responsibilities, and opportunities as are available to others.

**Misconception 2: "Special services are inconsistent with the normalization principle, which supports dumping people from institutions into the community without support"**

The normalization principle has been falsely interpreted to mean that mentally handicapped people should be placed in the community without any support or assistance, however essential it may be. On the contrary, physical placement in the community does not necessarily represent integration or normalization: the pertinent question is how closely the lives of mentally handicapped persons approach those of other members of the community. Where they do not, as in the case of someone isolated in a rat-infested boarding house, this represents false integration, *not* community living or normalization. The principle of normalization, on the contrary, supports, indeed insists upon the provision of whatever services, training, and support are required to permit living conditions and routines similar to that of others in the community. At a minimum, this would include appropriate housing, opportunities for some form of work (or education for children), and leisure.

Most "normal" people, as part of "normal" life, use specialized services when appropriate. For example, a person with heart trouble may consult a cardiologist; in extreme cases a pacemaker, a decidedly "unnormal" foreign object, may be surgically implanted in the body. The purpose of this abnormal treatment is to permit the continuation of everyday living patterns (i.e. "normal" living).

The normalization principle indicates that mentally handicapped people should also have access to those forms of "unnormal" assistance they require in order to take part in normal living, *on the same basis* as "special" services are provided to other members of society. Where possible, generic services (e.g. regular dentists) should be used. A word of caution: just as with some medical conditions where the treatment or cure may be worse than the disease, some special services, despite their benefits, may actually *detract* from, rather than enhance normal living. This is particularly true of institutions and is a danger of many segregated services.

**Misconceptions 3: "Normalization is an all or nothing concept, and applies only to mildly handicapped people"**

On the contrary, the principle of normalization applies to all, and indeed its implications may be most far-reaching for people with more severe handicaps. As Nirje has indicated,[5] the ideas which led to the development of the principle grew out of analyses of facilities and programs for severely handicapped people, in the attempt to make their living situation more similar to that of others. There are degrees of normalization, and the principle implies provision of a *range* of support and structure, depending upon the individual's need (e.g. a continuum of housing, including highly structured settings and various forms of cooperative living; work alternatives, including work stations, other low-support arrangements, as well as sheltered employment; etc.).

**Misconception 4: "Mentally handicapped people are best off with their own kind, protected from the rigours of society"**

This philosophy, however well-meaning, has led to the creation of large asylums and institutions where in the name of "protecting" people, they too often have been (and still are) subjected to inhumane treatment and living conditions. But even more significantly, as Dybwad[6] has discussed, the abilities of mentally handicapped people have been grossly underestimated. Given appropriate training and opportunity, they *can* function at levels never considered possible.[7] Thousands of "hopeless" cases, once freed from restrictive institutions, not only have demonstrated their ability to function more than adequately as *people*, but have expressed a clear preference for this lifestyle.

**Misconception 5: "Normalization is a Scandinavian concept inapplicable elsewhere"**

Normalization does *not* mean the application of Scandinavian services elsewhere, and in fact is neutral regarding cultural values. The specific implications of normalization are different for every culture since what constitutes normal living patterns and opportunities varies from society to society. Ironically, the principle may be easier to implement in many developing countries which do not have an entrenched infrastructure of facilities and programs or a history of segregating handicapped people from the community thus eliminating the necessity to dismantle before implementation.

**Misconception 6: "Normalization is a humanistic concept, but idealized and impractical"**

On the contrary, one of the major benefits of the principle is that it *is* practical, providing guidance for how we view and treat handicapped people, along with many specific implications for action. These implications are, and have been, subject to scientific test and scrutiny; very impressive results in many different contexts have been attained where the principle has been applied.

*"Those who don't benefit from history are doomed to repeat it."*

— Santayana

***You do a great disservice to an individual when you limit his or her potential***

## *Would you sleep, eat, work, and live here?*

◆

*The law mandates that:*

*"No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal assistance."*

***A CLANGER is that instant recognition of oddity.***

3

MODULE THREE

# Foundation Level Training

## Systems and Policies

Department of Human Services
Developmental Disabilities
Services Division

# SYSTEMS AND POLICIES

## Module Three

# OBJECTIVES

Module Three

# SYSTEMS AND POLICIES

Module 3 - Foundation Training

## LEARNING OBJECTIVES

***Primary Objective:*** Upon completion of this training and given the appropriate materials, the participant will be able to understand the system that shapes service delivery in the State of Oklahoma for people with developmental disabilities.

### *Secondary Objectives:*

- Discuss the services provided to individuals with developmental disabilities in the State of Oklahoma. Identify the people responsible for delivering these services.
- Describe the basic services provided by state employees and private provider agencies
- Describe the primary way services are provided in Oklahoma.
- List five different people who may be on an interdisciplinary team. Discuss their common goals.
- Recognize three elements of a successful habilitation program.
- Discuss the process an interdisciplinary team goes through in developing an individual plan.

# Training Information And Schedules

## Module Three

# Training Schedule

## *MODULE 3 - SYSTEMS AND POLICIES*

| Objectives | Key Points | Exercises/ Activities | Transparencies | Handouts | Media | Length |
|---|---|---|---|---|---|---|
| 1. Discuss the services provided to individuals with developmental disabilities in the State of Oklahoma. Identify the people responsible for delivering these services. | * Federal government<br>* State government<br>* Funding<br>* Private agencies<br>* Advocacy groups | Group Presentations: (optional)<br>"Agencies"<br>"Residential Options" | 3.1 Service System<br>3.2 Funding Sources<br>3.3 Federal Government<br>3.4 Organizational Chart<br>3.5 Organizational Chart<br>3.6 State Department<br>3.7 State Department<br>3.8 State Department<br>3.9 Advocacy<br>3.10 Advocacy Groups | 3A State Definition<br>3B DDSD Offices<br>3C Resource Directory<br>3D Rehabilitation Offices<br>3E Home and Community-Based Waivers<br>3F Acronym Guide/Funding Streams | | 1hr/30min |
| 2. Describe the basic services provided by state employees and private provider agencies. | * Continuums<br>* Types of services<br>* Residential services<br>* Case management<br>* Support services | "Speakers" (optional) | 3.11 Continuums<br>3.12 Residential<br>3.13 In Home...<br>3.14 Vocational/Case Management<br>3.15 Support Services | 3A.1 Overview<br>3A.2 Myth vs. Reality<br>3A.3 Guide to Support<br>3A.4 Health Care<br>3A.5 Programs and Services<br>3A.6 Directory | Video: "Choices" | 1hr/30min |
| 3. Describe the primary way services are provided in Oklahoma. | * The Individual Plan | | | | | 15min |
| 4. List five different people who may be on an interdisciplinary team. | * The Interdisciplinary Team | | | | Audio: "The Exceptional Parent Blues"<br>Video: "A Change of Seasons | 1hr/15min |
| 5. Recognize three elements of a successful habilitation program. | *Elements | | 3.16 Elements | | | 30min |
| 6. Discuss the process an interdisciplinary team goes through in developing an individual plan. | * Assessment<br>* Desire/long term view<br>* Limitations | Activity: "Non-verbal Trust Walk" | 3.17 Developing the plan (2) | | | 1hr |

# Systems and Policies

# MODULE OUTLINE

## I. THE SERVICE SYSTEM

A. FEDERAL GOVERNMENT
  1. Program goals
    a. Independence
    b. Productivity
    c. Integration
    d. Choice
  2. Federal Programs
    a. Department of Health and Human Services
      - Supplemental Security Income (SSI)
      - Health Care Financing Administration (HCFA)
    b. Department of Housing and Urban Development
      - Direct Loans for Housing for People Who Are Elderly or Handicapped
      - Rental Rehabilitation Program
      - Supportive Housing Program
      - Community Development Block Grants (CDBG)

B. STATE GOVERNMENT
  1. History
  2. Department of Human Services
    a. Developmental Disabilities Services Division
    b. Rehabilitation Services Division
      - Rehabilitation and Visual Services
      - Supported Employment
      - Rehabilitation Teaching Services
      - Schools for the Deaf and Blind
      - Other Services
    c. Medical Services
      - Medicaid
      - EPDST
      - Children with Special Needs
      - SSI
      - Child Welfare

OUTLINE - MODULE 3 (CONT.)

- d. Other Services
  - Non-technical Medical Care
  - Home Maintenance Medical Care
  - Food Stamp and Energy Assistance
  - Payment for Daycare
- 3. State Department of Education
  - a. Shapes policy
  - b. Monitors compliance
  - c. Due Process hearings
  - d. Coordination of in-school programs
- 4. State Department of Health
  - a. Prevention of disease
  - b. County health departments
  - c. Child guidance clinics
  - d. Newborn hearing screening
  - e. Genetic counseling
  - f. Residential licensing
  - g. Education in human sexuality
  - h. Child abuse prevention services
- 5. The Department of Mental Health and Substance Abuse
- 6. Indian Health Agency
- 7. The Oklahoma Commission on Children and Youth
  - a. Interagency Coordinating Council for Early Childhood Intervention
  - b. Interagency Coordinating Council for Special Services to Children and Youth
- 8. Oklahoma Areawide Services Information System (OASIS)

C. DISTRIBUTION OF FUNDING

D. PRIVATE AGENCIES AND ORGANIZATIONS
- 1. Donna Nigh Foundation
- 2. The Community Services Council of Greater Tulsa

E. ADVOCACY GROUPS
- 1. Government Advocacy Groups
  - a. Office of Client Advocacy
  - b. Oklahoma Planning Council for Developmental Disabilities
  - c. Disability Law Center

OUTLINE - MODULE 3 (CONT.)

- d. University Affiliated Programs
- e. Oklahoma Office of Handicapped Concerns
  - The Oklahoma Client Assistance Program
- f. Office of the Guardian Ad Litem

2. Private Advocacy Groups
   - a. Oklahoma Community Providers
   - b. Pro-Oklahoma
   - c. Positive Reflections
   - d. Tulsa Association for Retarded Citizens (TArc)
   - e. Oklahoma People First

## II. RESIDENTIAL OPTIONS

- A. CONTINUUMS
  - 1. Cost
  - 2. The Procrustes Myth
    - a. Individual-Up service system
- B. TYPES OF RESIDENTIAL SERVICES
  - 1. Assisted Living
  - 2. Supported Living
  - 3. Habilitation Services
  - 4. Adult Companion
  - 5. Foster Care
  - 6. Group Homes
  - 7. Resource Centers
  - 8. Nursing Homes
- C. IN-HOME, OUT-OF-HOME SERVICES
  - 1. Outline
  - 2. Residential Employees
- D. CASE MANAGEMENT
- E. SUPPORT SERVICES
  - 1. Assessment Services
  - 2. Communication Services
  - 3. Skill Development Services
  - 4. Behavioral Support Services
  - 5. Health Care Services
    - a. Skilled nursing
    - b. Dental services
    - c. Nutritional services

OUTLINE - MODULE 3 (CONT.)

        - d. Psychiatric services
        - e. Hearing treatment
        - f. Oral-motor activities
    - 6. Accessibility
        - a. Architectural modification
        - b. Assistive technology
        - c. Mobility services
        - d. Transportation

## III. HOW SERVICES ARE PROVIDED

- A. THE INDIVIDUAL PLAN

## IV. WHO PARTICIPATES

- A. THE INTERDISCIPLINARY TEAM
    - 1. Team Composition
    - 2. Most Important Member

## V. ELEMENTS OF A GOOD PROGRAM

- A. A WORKING PROGRAM
- B. MAXIMUM CHALLENGE
- C. RISK-TAKING
- D. MEASURING RESULTS
- E. GOOD STAFFS
- F. WE ARE THE LEARNERS

## VI. DEVELOPING THE PLAN

- A. SELF ASSESSMENT
- B. CONSUMER DESIRE/LONG TERM VIEW
- C. IHP LIMITATIONS

# LECTURE AND ACTIVITIES

## Module Three

# Systems and Policies

# MODULE OUTLINE

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- B. STATE GOVERNMENT . . . . . . . . . . . . . . . . . . . . . . 9
- C. DISTRIBUTION OF FUNDING . . . . . . . . . . . . . . . . . . 24
- D. PRIVATE AGENCIES AND ORGANIZATIONS . . . . . . . . . . . 24
- E. ADVOCACY GROUPS . . . . . . . . . . . . . . . . . . . . . . 25

**II. RESIDENTIAL OPTIONS . . . . . . . . . . . . . . . . . . . . . . . 32**

- A. CONTINUUMS . . . . . . . . . . . . . . . . . . . . . . . . . 33
- B. TYPES OF RESIDENTIAL SERVICES . . . . . . . . . . . . . . 36
- C. IN-HOME, OUT-OF-HOME SERVICES . . . . . . . . . . . . . . 38
- D. CASE MANAGEMENT . . . . . . . . . . . . . . . . . . . . . . 42
- E. SUPPORT SERVICES . . . . . . . . . . . . . . . . . . . . . . 43

**III. HOW SERVICES ARE PROVIDED . . . . . . . . . . . . . . . . . . 47**

- A. THE INDIVIDUAL PLAN . . . . . . . . . . . . . . . . . . . . 47

**IV. WHO PARTICIPATES . . . . . . . . . . . . . . . . . . . . . . . . 49**

- A. THE INTERDISCIPLINARY TEAM . . . . . . . . . . . . . . . . 49

**V. ELEMENTS OF A GOOD PROGRAM . . . . . . . . . . . . . . . . . . 52**

**VI. DEVELOPING THE PLAN . . . . . . . . . . . . . . . . . . . . . . 57**

# SYSTEMS AND POLICIES

Module 3 - Foundation Training

***Since you are probably a little more than halfway through the training, now might be a good time to let the participants have some "release" time. An informal talk about what they are hoping to accomplish in their new positions, the problems they feel they might encounter, any fears they may have, etc., might be in order here. Encourage the group to share questions they may have about the training to date and answer as honestly as possible.***

***The next section might be difficult to follow for some participants so present the material as clearly as possible and encourage them to take notes and ask questions.***

## INTRODUCTION

INTRODUCTION

The service landscape in Oklahoma is made up of a large community of consumers, professionals, service providers, parents, families, and advocates. Each has an integral role to play in the success of the service delivery system. If society is to be changed, the people who work in the field of developmental disabilities can make an enormous difference. More importantly, the presence of people with disabilities in neighborhoods, workplaces, and in shopping malls, theaters, and grocery stores, will help their fellow Oklahomans move beyond stereotypes of the past. This module is intended to give a bird's eye view -- the "big picture, if you will -- of the following:

- Where the money comes from to pay for services.
- Who the people and organizations are that deliver those services and goods.
- Who the people and organizations are that lobby the legislature for support, monitor the quality of the services provided, and advocate on behalf of children and adults with disabilities.

***Objective 1:***

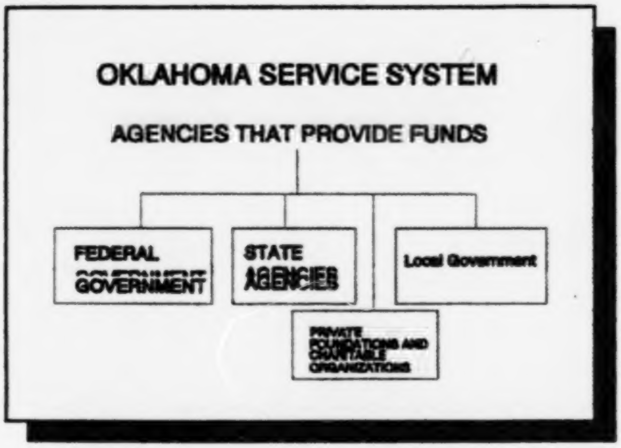
***Discuss the services provided to individuals with developmental disabilities in the State of Oklahoma. Identify the poeple responsible for delivering these services.***

**Objective 1**

## STRUCTURE OF THE SERVICE SYSTEM

STRUCTURE OF THE SERVICE SYSTEM

The service system for people with developmental disabilities is shaped by three levels of influence: federal laws and regulations, state laws and agency policies, and local and private efforts.



OKLAHOMA SERVICE SYSTEM

AGENCIES THAT PROVIDE FUNDS

FEDERAL GOVERNMENT

STATE AGENCIES

Local Government

PRIVATE FOUNDATIONS AND CHARITABLE ORGANIZATIONS

**SHOW** *Transparency 3.1 (Service System)*

Transparency 3.1
(Service System)

# THE FEDERAL GOVERNMENT

THE FEDERAL
GOVERNMENT

**SHOW** *Transparency 3.2 (Funding sources)*

Transparency 3.2
(Funding
Sources)

***Explain how:***

- ***Federal agencies and programs are funded.***
- ***Money is channeled from federal agencies to state agencies to specific programs.***

***Using a flip chart, list the four federal policy program goals and discuss how they shape services.***

## Federal Policy Program Goals

Federal Policy Goals

Four federal policy program goals shape the way we think about services for people with developmental disabilities. They are:

**Independence**
**Productivity**
**Integration**
**Choice**

These are contained in the Developmental Disabilities Assistance and Bill of Rights Act which is written with the following goals:

- To enable people with disabilities to achieve their maximum potential through increased **independence, productivity**, and **integration** into the community, and;
- To protect the legal and human rights of persons with developmental disabilities.

Independence

**Independence** means that people have control and choice but does not mean that people have to do things without the help and support of others. People are interdependent which means that they rely upon one another to meet their needs. Interdependence is not the opposite of independence. People are both independent and interdependent -- people who have control and choice in their lives often depend upon each other to live more fully and enjoy life more.

Productivity

**Productivity** is "an engagement in income-producing work by a person that is measured through improvements in income level, employment status, or job advancement. Or, it is the "engagement by a person which contributes to a household or community."

Integragtion into community

**Integration into the Community** is the use of the same resources by a person with disabilities as those used by, and are available to, other citizens. It also includes participation in the same community activities as other citizens engage in as well as regular contact with nondisabled citizens. It involves participation in homes or in home-like settings which are close to community resources.

The term "integration" refers to three interrelated ideas. People with disabilIties should have access to the same resources as people without disablIities. Further, they should use them at a time when people without disabilities use them and actively be involved with people without disabilities. Living in the community in homes is the final part of the definition. The three aspects of integration have been expanding and are being replaced by the concept of inclusion. Inclusion means that people with disabilities need to be included in the same communities and activities as people without disabilities (as discussed earlier).

Choice

**Choice** is the expression of preference or active selection among two or more alternatives, based on prior experience, current needs, and future goals. In other words, a person makes a choice when he or she states a preference among two or more alternatives. Types of choices may include:

Where to live, work, and get services
Goals and objectives in everyday life
Ways to meet goals and objectives
Expression of preferences in every-day life

Choices in the past were limited for people with developmental disabilities. To achieve independence, productivity, and integration while maintaining an individual's human and legal rights, choice must be considered. Informed choices cannot be made without knowing that other options exist.

***********

The above policy goals influence all federal departments in their delivery of service to individuals with developmental disabilities. Although the Developmental Disabilities Administration puts a relatively small amount of money into the system, they do develop policy through incentive grants and general influence.

**SHOW** ***Transparency 3.3 (Federal Government)***

***The following information may be difficult for trainees to understand. It is helpful if the trainer reads the material and is very familiar with the programs described.***

Transparency 3.3 (Federal Government)

# FEDERAL PROGRAMS

FEDERAL PROGRAMS

## *I. U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)*

DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

Supplemental Security Income (SSI)

- **Supplemental Security Income (SSI)** provides a national minimum income for people who are aged, disabled, or blind. The program is designed to assist individuals with disabilities who are below specified income and resource limits. Various eligibility criteria apply to people age 65 and over; people 18 or older; and children with severe disabilities.

  In 1992, a person who lives independently could receive as much as $407 a month from SSI (or $661 for an eligible couple). Of course, these figures do change over time to keep up with inflation. Individuals living in someone else's household, including that of their parents, qualify for a lower amount. SSI recipients are also likely to qualify for Food Stamps and Medicaid (medical care).

Health Care Financing Administration (HCFA)

- **Health Care Financing Administration (HCFA)**
  **Title XIX - Medicaid Services**
  HCFA administers the Medicaid program. Funding under Medicaid includes payments to doctors, hospitals, pharmacies and other health providers for services to medically needy persons. Funding is also available for care in nursing homes, specialized nursing facilities, (such as pediatric nursing facilities), intermediate care facilities, intermediate care facilities for people with mental retardation - (both public (like THMC, NORC, and SORC), and privately operated facilities). The Medicaid waiver programs, such as the Home and Community-Based Waiver, model waivers and the Alternative Disposition Plan (ADP) waivers are also administered by HCFA. The ADP waivers

provide funding for community services for people with mental retardation or related conditions who were living in nursing homes.

HCFA develops the regulations for these programs, monitors the use of Title XIX funds, and ensures compliance with regulations.

Medicaid (Title XIX)

**Medicaid (Title XIX)** was originally passed into law in 1965 and has since been broadened to include not only provision of medical services but many other services as well. For example, the cost of institutions, nursing homes, group homes, and since 1985 a wide variety of in-home support is funded by Medicaid. Each state's grant from the federal government is determined by two things:

- Which services the state chooses to provide (states are not required to provide all services under Medicaid);
- The amount of federal "match" funds sought by the state. For example, poorer states have a twenty-five/seventy-five percent match; that is, they get seventy-five cents from the federal government for every twenty-five cents they put in. More affluent states get a fifty-fifty match; that is, they receive fifty cents for each fifty cents they match. Oklahoma currently receives approximately a seventy-thirty match; that is, they receive seventy cents for every thirty cents they match.

**Medicare provides health and hospital care for all Americans aged 65 or older.**

## *II. U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD)*

U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD)

The United States Congress has mandated the Department of Housing and Urban Development to create conditions so every family can have decent and affordable housing, to ensure equal housing opportunities, and to strengthen and enrich our nation's communities. HUD administers many programs which assist individuals and communities to develop homes and housing which are accessible to people with physical disabilities. A few of the major programs are:

Direct Loans For Housing For People Who Are Elderly Or Handicapped

- **Direct Loans for Housing for People Who are Elderly or Handicapped** (Section 202) - is the standard financing mechanism for subsidizing housing for people who are elderly and people with disabilities. It provides 100% direct mortgage loans and rent subsidy for residents, funding for the development of independent-living apartment complexes (up to 24 units at one site), as well as group homes (up to 15 residents).

Rental Rehabilitation Program

- **Rental Rehabilitation Program** - provides grants to rehabilitate existing rental units as well as rental assistance to low income households. This program minimizes displacement and is designed to attract private financing.

Supportive Housing Demonstration Program, Permanent Housing Component

- **Supportive Housing Demonstration Program, Permanent Housing Component** - provides advances or grants to states on behalf of project sponsors, private nonprofit organizations, or public housing authorities. These monies help pay for the cost of:
  1) acquiring and/or rehabilitating existing buildings for permanent housing of not more than eight homeless people with disabilities;
  2) retirement of mortgage debt;

- Community Development Block Grants (CDBG) - provide grants to communities for use in financing projects that foster development of viable urban communities. At least 51% of the funds are to be targeted to projects benefiting low and moderate income persons which often includes people with disabilities. Most communities attempt to make their CDBG money go farther by using them to provide a portion, rather than all the financing needed for a project. CDBG can pay for low interest second mortgages, low interest construction financing, building acquisition, relocation, demolition, rehabilitation, and in some cases, new construction.

Community Development Block Grants (CDBG)

# STATE GOVERNMENT AGENCIES

STATE GOVERNMENT AGENCIES

## HISTORY OF COMMUNITY SERVICE DEVELOPMENT IN OKLAHOMA

History of Community Service Development

In 1963, the State Legislature transferred the three state schools for persons with mental retardation to the Department of Human Services from the State Board of Mental Health. Both the Enid and Pauls Valley facilities had served varying functions as state institutions since early statehood.

Oklahoma first initiated community services in the mid-1960's through its sponsorship of sheltered workshops. This program grew through the 1970's and included 40 workshops by 1980. Until this time, community services in the state were funded exclusively with funds provided by the Oklahoma Planning Council on Developmental Disabilities.

Group home program

In 1980, the Oklahoma Legislature authorized for the first time funding ear-marked for community services to further expand vocational services. In addition, at this time, through partnership with the First Lady, Donna Nigh, Oklahoma initiated its group home program.

By the mid-1980's, the sheltered employment program had grown to approximately 62 sites across the state and a network of approximately 70 group homes had emerged. Throughout this process, Donna Nigh was instrumental in lobbying both the Governor and the Legislature for initial, as well as continuation, of funding for community programs. In recognition of her efforts, the community residential program of Oklahoma became known as the Donna Nigh Group Home Program. Her commitment to the field later led to the creation of the "Donna Nigh Foundation" by then Governor George Nigh.

Creation of DDSD

In 1983, state supports for individuals with mental retardation were organized under the Developmental Disabilities Services Division (DDSD). One of the initial efforts of the new division was the creation of a coordinated plan for the expansion of community based service options. As an outgrowth of this plan, Oklahoma not only achieved the expansion of group homes and sheltered workshops as discussed earlier, but in 1985, gained authorization of a Home and Community-Based Waiver (HCBW) providing Federal financial support for an array of professional and para-professional supports now available in communities across the state. Today, Oklahoma's array of supports funded through this waiver are among the most expansive and flexible in the nation.

**SHOW** ***Transparency 3.4 and Transparency 3.5 (Organizational Charts)***

- ***It might be helpful to list state agencies and what they do on a flip chart***
- ***You may also break into small groups and let each group present an agency. It often makes the material easier to absorb if a group gets involved in the actual presentation.***

Transparency 3.4 and Transparency 3.5 (Organizational Charts)

**PRESENT** We will focus today on the state system of providing services through the Developmental Disabilities Services Division (DDSD), but we need to keep in mind that there are many other state and local services which either impact or are resources for people with developmental disabilities.

**Oklahoma state agencies providing services:**

State agencies

- **Oklahoma Department of Human Services**
- **Oklahoma Department of Education**
- **Oklahoma Department of Health**
- **Oklahoma Department of Mental Health and Substance Abuse**
- **Oklahoma Commission on Children and Youth**

# *I. OKLAHOMA DEPARTMENT OF HUMAN SERVICES*

OKLAHOMA DEPARTMENT OF HUMAN SERVICES

**HANDOUT** ***Handouts 3A - 3F (State Infomation)***

Handouts 3A - 3F (State Information)

**SHOW** ***Transparency 3.6 (State Services)***

Transparency 3.6 (State Services)

In Oklahoma, the Department of Human Services (DHS) is responsible for many of the services to people with developmental disabilities. Originally called the Department of Public Welfare, DHS was established in 1936 by a vote of the people. Article XXV of the Oklahoma State Constitution directs DHS to "administer and carry into execution all laws enacted which provide for the relief and care of needy aged persons who are unable to provide for themselves, and other needy persons who, on account of immature age, physical infirmity, disability, or other cause are unable to provide or care for themselves." Within the DHS, there are many programs which may benefit people with developmental disabilities.

## ■ DEVELOPMENTAL DISABILITIES SERVICES DIVISION (DDSD)

Developmental Disabilities Services Division (DDSD)

The Developmental Disabilities Services Division is headed by Jim Nicholson and is responsible for providing both institutional and community-based service programs for persons with mental retardation and other developmental disabilities. Medicaid is the single greatest source of federal funds.

DDSD emphasizes community-based services and supports and currently employs resource developers to make specialized services more available within the community.

## ■ REHABILITATION SERVICES DIVISION (RSD)

Rehabilitation Services Division (RSD)

**SHOW** ***Transparency 3.7 and 3.8 (Agency Services)***

Transparency 3.7 and 3.8 (Agency Services)

In addition to the vocational services funded through the Developmental Services Division, another division of DHS, Rehabilitation Services Division, provides vocational support to people with disabilities.

## Rehabilitation and Visual Services

Rehabilitation and visual services

In addition to the general rehabilitation program which provides counseling and training, job development, job placement and physical and mental restoration, RSD manages several other programs which may be useful to our clientele.

## Supported Employment

Supported employment

***Explain to trainees that both DDSD and DVR are involved in providing supported employment.***

This is a specialized program offering job development, job placement, training and on-going support for people with disabilities so severe they are not otherwise considered candidates for competitive employment and are expected to require life-long support in order to continue employment.

Although supported employment is described under rehabilitation services division umbrella, it needs to be emphasized that this concept -- individuals working in integrated, normal work settings in the community -- is also the type of service provided through the Developmental Disabilities Vocational Services network. As was noted earlier, people with developmental disabilities may require lifetime of support to stay in those settings.

## Rehabilitation Teaching Services

Rehabilitation teaching services

These services are available to persons of any age who are legally blind. Rehabilitation teachers work with people in adults who meet eligibility criteria.

### Schools for the Blind and Deaf

Schools for the blind and deaf

The Oklahoma School for the Blind is located in Muskogee. Sulphur is the home of the Oklahoma School for the Deaf. Both schools have day and residential services as well as programs for children with multi-handicaps. They also operate limited outreach programs.

### Other Services

Other services

Among the other services available from Rehabilitation Services are:

- Interpreter services
- Library for the Blind and Physically Handicapped
- Orientation and Mobility Specialists
- Deaf/Blindness and Aging Specialists
- Independent Living Programs
- Transitional Living Centers

## ■ MEDICAL SERVICES

### Medicaid

MEDICAL SERVICES

Medicaid

The Oklahoma Home and Community-Based Waiver for People with Mental Retardation and the ADP Waiver are part of this program. However, most adults and many of the children we serve are eligible for the regular Medicaid program. Direct payments are made to health care providers, hospitals, nursing homes, dentists, and pharmacies.

### EPSDT (Early and Periodic Screening, Diagnosis

**and Treatment)**

EPSDT

EPSDT provides health screening and follow-up treatment for children who are Medicaid eligible. If a medical service is prescribed through this screening, it can be paid for even if it is not one of the services available normally through the Medicaid State Plan.

### Children with Special Needs (Formerly Crippled Children's Program)

Children with special needs

This program supplements services available through Medicaid. Some children with severe disabilities are eligible for this program even when financially ineligible for Medicaid.

## SSI - Disabled Children's Program

SSI - Disabled children's program

This program provides health and social services for children under the age of 16 who receive SSI benefits.

### Child Welfare

Child welfare

Child Welfare provides foster care and adoption services. Since DDSD does not provide foster care for children under six years of age, Child Welfare provides foster care services for young children with disabilities in need of such care.

Child Welfare and Adult Protective Services receive reports on abuse or neglect, investigate allegations and provide protective services when necessary. The Office of Client Advocacy also receives reports and investigates cases of abuse and neglect.

## ▪ OTHER FREQUENTLY USED SERVICES

Other Frequently Used Services

### Non-Technical Medical Care

Non technical medical care

Nurse-supervised in-home services by trained providers help low-income people who are disabled or elderly and whose health problems would otherwise require nursing home care.

### Home Maintenance Aide Services

Home maintenance aide services

Non-medical services to help improve the client's functioning in the home.

### Food Stamps and Energy Assistance

Food stamps and energy assistance

Available to low income households.

**Payment for day care**, AFDC, or any of the other services provided under the DHS umbrella are available to our clientele if they meet eligibility requirements. The local DHS case worker can assist with these services.

Payment for day care

# *II. STATE DEPARTMENT OF EDUCATION*

STATE DEPARTMENT OF EDUCATION

The State Department of Education (SDE) in Oklahoma provides few services directly. Almost all services are the responsibility of the school district in which the child resides. The SDE is a conduit through which state and federal funds flow to the local school districts. Most of these funds are allocated through a formula based on attendance and other district demographics including:

- Population density
- Level of teacher education
- Number of children eligible for school lunch program
- Number and types of special education and other special population students

Some funds are allotted based on grant applications and approvals.

Shapes Policy

**The SDE also shapes policy, monitors the quality of programs, requires financial accountability, and provides training and technical assistance.**

The Special Education Section of the State Department of Education assists in these functions for special education students and programs. They issue proposal applications for available special funds, review the applications, and make recommendations to the State Board of Education for grant awards.

Monitors Compliance

**They also monitor special education programs for compliance with state and federal laws**, and provide training and technical assistance as well as collect data required for state and federal reports.

Due Process Hearings

The SDE Special Education Section receives and responds to informal and formal complaints from parents and others about the services provided by the local schools. When a due process hearing is requested, the Special Education Section arranges for an impartial hearing officer and coordinates the hearing with the parties involved. Hearings may be held concerning the identification, evaluation, or educational placement of a child, or on the provision of a free and appropriate public education. Hearings may be held at the request of the parent or of the school.

The SDE Special Education Section has staff members who are specialists in the various categories of special education and who are excellent resources.

Coordinates In-school Programs

**The Special Education Section coordinates two in-home pre-school programs**; Project ECHO serves pre-school children with hearing impairments, and Project INSITE serves pre-school children with multiple sensory disabilities. Both programs send parent advisors into the home to assist families in promoting the development of their children.

The Special Education Section has a Hissom Settlement Office in Tulsa with a staff of five to assist in the transition of Hissom students into the local schools.

**Children who meet the special education criteria are eligible for services from age three years until their 22nd. birthday** unless they have graduated and received a diploma at an earlier age.

The SDE is designated as the lead agency for services to children under the age of three with developmental delay. This program is authorized through Part H of the Individuals with Disabilities Education Act. In Oklahoma, the program is called SoonerStart.

The SDE also operates 21 Regional Education Service Centers which screen and evaluate students for special education, provide consultation and specialized materials to the schools.

The telephone number for the Special Education Section is:
**(405) 521-3351**

# *III. THE STATE DEPARTMENT OF HEALTH*

STATE DEPARTMENT OF HEALTH

**SHOW** ***Transparency 3.8 (State Departments)***

Transparency 3.8 (State Departments)

The focus of the State Department of Health (SDH), as well as local health departments, is the prevention of disease, illness, accidents, disabilities, and other health problems. These include primary prevention activities, such as immunization programs and secondary prevention activities (designed to reduce the effects or complications of health problems).

Prevention Of Disease

The SDH provides some services directly, but many services are delivered through local county health departments with support from the SDH. There are county health departments in 69 of Oklahoma's 77 counties. Some of the services available through the local health departments are immunizations, well-child clinics, family planning, environmental health services and visiting nurse programs.

County Health Departments

Many of the health departments also have child guidance clinics. There are 43 full-time child guidance clinics and 57 satellite clinics for a total of 100 state-wide. These clinics provide psychological evaluation and counseling, speech and language evaluations and therapy, audiological, social and child development services. Not all of the clinics have all services. Young children and their families receive priority when resources are limited.

Child Guidance Clinics

**Some of the clinics provide services to the local schools through contract agreements.** The SoonerStart therapy services are also provided in conjunction with child guidance clinics.

Other services provided through the State Health Department include:

Newborn Hearing Screening

- **Newborn Hearing Screening** - This program is designed to identify children with hearing loss at an early age so that medical and educational interventions can lessen effects of the hearing problems. This program will be expanded to screen and track babies at risk for other disabilities and health problems.

Genetic Counseling Clinics

- **Genetic Counseling Clinics** - These clinics are provided in cooperation with the DHS for people who have reason to be concerned about inherited diseases or disabilities.

Residential Licensing

- **Residential Licensing** - The health department inspects and licenses the ICFs/MR programs and group homes.

Education in Human Sexuality

- **Education in Human Sexuality** - This service is primarily available to staff in the county health departments, but upon request and availability of time can be accessed by others. DDSD has been able to use this service on a limited basis for training program staff and consumers.

Child Abuse Prevention Services

- **Child Abuse Prevention Services** - This program is administered by the Child Guidance Service and has child abuse prevention projects in 76 of Oklahoma's 77 counties. This office works with local, district and state task forces on child abuse prevention. A lending library resource catalog is available from them and includes books, videos, and curriculum materials on child abuse prevention and parent education. These materials are available for check-out by professionals and community leaders involved in child abuse prevention. To obtain a copy of the catalog, call **(405) 271-4477**.

## *IV. THE DEPARTMENT OF MENTAL HEALTH AND SUBSTANCE ABUSE (DMHSA)*

THE DEPARTMENT OF MENTAL HEALTH AND SUBSTANCE ABUSE (DMHSA)

The mental health, substance abuse, and domestic violence service system is composed of state-operated facilities and private providers who deliver services pursuant to contracts with the Department of Mental Health and Substance Abuse Services (DMHSAS).

State operated facilities include four state mental hospitals (three adults; one child and adolescent), two inpatient substance abuse treatment facilities, five community mental health centers (CMHC), three of which also provide inpatient services, and a crisis intervention center in Oklahoma City.

Contracts for services provided through the private sector include sixteen private non-profit community mental health centers, and contracts for substance abuse prevention and treatment, outpatient mental health services, crises intervention services, domestic violence shelters, transitional living facilities, as well as residential care services. The contracts are made with CMHC's substance abuse treatment providers, domestic violence service providers, and other community services.

## *V. INDIAN HEALTH SERVICE*

INDIAN HEALTH SERVICE

The Federal Indian Health Service (IHS) operates or contracts with Indian tribes to operate seven hospitals and 24 health centers throughout Oklahoma. They provide the full range of health care services to native Americans in Oklahoma from prenatal care to well-child check-ups, acute care, maternity services, and physical therapy.

# VI. THE OKLAHOMA COMMISSION ON CHILDREN AND YOUTH

THE OKLAHOMA COMMISSION ON CHILDREN AND YOUTH

The Oklahoma Commission on Children and Youth (OCCY) monitors the development and quality of services to Oklahoma's children. In addition to inspecting state, local and privately run residential child care facilities, OCCY conducts planning, coordinating, and interagency activities. With input from regional planning and coordinating boards, the OCCY prepares and presents a children's budget for the state for presentation to the legislature.

The OCCY administers two planning and coordinating committees which impact children with disabilities.

Interagency Coordinating Council for Early Childhood Intervention

- **The Interagency Coordinating Council for Early Childhood Intervention**
  This council has the responsibility to advise and assist the lead agency in the development and implementation of policies for the SoonerStart Early Intervention Program. OCCY administers the Interagency Coordinating Council. The 15 member council is comprised of representatives from major state agencies, public schools, the legislature and parents. The members are appointed by the Governor.

  SoonerStart serves infants and toddlers with developmental delays from birth to age three years. This program is the result of, and operates through, true interagency collaboration.

Interagency Coordinating Council for Special Services to Children and Youth

- **The Interagency Coordinating Council for Special Services to Children and Youth. (Special Services Council)**
  The Interagency Coordinating Council for Early Childhood Intervention worked so well that the state legislature passed a law establishing a similar council to develop a coordinated system of services for children ages

three through 21 years. This council has been functioning since July 1991. A plan for coordinated services has been developed to submit to the legislature but has not yet been fully implemented. The plan emphasizes coordinated service delivery among agencies responsible for various aspects of Oklahoma's system for helping children with disabilities and their families. Agencies involved in getting services to such children include the public schools, State Department of Education, State Department of Vocational-Technical Education, State Department of Health, Department of Human Services, and the Department of Mental Health and Substance Abuse Services.

Recommended in the service plan is development of a network of nonprofit, parent-operated Family Resource Centers to offer information and support to families. The plan also proposes training for volunteer mediators of the State Supreme Court's Early Settlement Centers to assist in mediating disputes between parents and schools and other service providers. Funding issues are also addressed.

The number for SSC is **(405) 521-4016**.

## *VII. OKLAHOMA AREAWIDE SERVICES INFORMATION SYSTEM (OASIS)*

OKLAHOMA AREAWIDE SERVICES INFORMATION SYSTEM (OASIS)

OASIS is a centralized directory of services available statewide for use by individuals with disabilities. OASIS is a computerized information database listing public and private service providers across Oklahoma. The OASIS information counselor can usually respond immediately to requests from parents, consumers, or professionals with up-to-date information on available services. The number for OASIS is **(405) 271-6302** (Oklahoma City) **or**
**1-800-42-OASIS**.

# DISTRIBUTION OF FUNDING

DISTRIBUTION OF FUNDING

**Federal and state distribution of funds is provided to the various agencies in the following percentages:**

| Funding for DDSD | Funding for SDE |
|---|---|
| 51% from State | 94% from State and Local |
| 49% from Federal | |

***Private agencies are an integral part of the service system. Before presenting this section, have the participants make of list of three or four things they can think of that private agencies contribute. After you have presented this section, make a list of contributions on a flip chart and see if participants' awareness has increased.***

# PRIVATE AGENCIES AND ORGANIZATIONS

PRIVATE AGENCIES AND ORGANIZATIONS

In addition to funding by federal and state agencies, there are many private agencies and organizations that fund services to individuals with disabilities. When looking for these, remember to check with tribal associations as well as with churches and civic organizations (i.e., Kiawanis, Lion's clubs, Sertoma, etc.). A brief listing of private and volunteer agencies follows.

## The Donna Nigh Foundation

The Donna Nigh Foundation

The Donna Nigh Foundation is a private, non-profit foundation created to assist people with mental retardation in areas which are not otherwise funded or are currently underfunded. The number for the Donna Nigh Foundation is **(405) 341-6927**.

## The Community Services Council of Greater Tulsa

The Community Services Council of Greater Tulsa

The Council is a United Way agency engaging in the planning, coordinating, research, information and referral of services. One of the projects managed is ETCH (Employees in Tulsa Care and Hire) which provides information and technical assistance to employers in the process of employing individuals with disabilities.

**FOR INFORMATION CONCERNING OTHER SPECIFIC DISABILITIES, PARENT GROUPS AND SERVICE PROVIDERS, CONTACT OASIS**

**1-800-42-OASIS or**

**(405) 271-6302 in Oklahoma City**

# ADVOCACY GROUPS

**SHOW** ***Transparency 3.9 and 3.10 (Advocacy Groups)***

Transparency 3.9 and 3.10 (Advocacy)

***Discuss Advocacy Groups:***

- ***What is advocacy?***
- ***Who are advocates?***
- ***How involved do advocates get?***
- ***Why were groups formed specifically for advocacy?***
- ***List some Oklahoma advocacy groups.***

Advocacy is acting on behalf of another person. The term is used to describe programs designed to defend the rights and interests of people with disabilities who have difficulty in defending their own rights and interests. An advocate, however, is not necessarily sponsored by a formal program. She or he may be a friend, a residential staff member, a job coach, a parent or foster parent, a lawyer, a guardian, a teacher, or a case manager who takes specific action to defend the rights and interests of a loved one, student, or client.

**The degree of involvement may include:**
- **(a) insuring due process or having a right enforced;**
- **(b) engaging in a compensatory justice of making things equal for all; or,**
- **(c) correcting measures which are aimed at making up for previous disadvantages the group or individual has suffered.**

Government Advocacy Groups

## ■ GOVERNMENT ADVOCACY GROUPS

Office of Client Advocacy

### OFFICE OF CLIENT ADVOCACY (OCA)

This office, which is located in the Department of Human Services, investigates allegations of abuse, neglect, or mistreatment of people who are housed in one of the Department of Human Services operated facilities. The OCA also investigates allegations of abuse, neglect, or mistreatment of custody or non-custody children in out-of-home placements, including but not limited to specialized community homes, jails/detention centers, hospitals, psychiatric facilities and treatment programs, and any child care facility (whether licensed or unlicensed) excluding day care centers and day care homes.

The OCA does not investigate allegations of the mistreatment of adults or children in foster homes or those living with relatives.

The OCA is assigned the responsibility of resolving grievances and investigation of allegations of mistreatment of Hissom class members, whether or not they still live at Hissom. The phone number for OCA is **1-800-522-8014** or **(405) 521-3491.**

## THE OKLAHOMA PLANNING COUNCIL FOR DEVELOPMENTAL DISABILITIES

Oklahoma Planning Council for Developmental Disabilities

The mission of the Council is to promote quality services and programs as well as advocate for persons with developmental disabilities. The council awards grants for innovative projects which encourage integration, independence and productivity. To accomplish this mission, the 24 member council can engage in needs assessment, policy planning, promotion of legislation, systems advocacy, public education, sponsorship of model programs, and the evaluation and monitoring of state activities.

The Council is charged with supervising the development of a state plan which describes the quality, extent, and scope of needed services provided to people with developmental disabilities. The Council monitors and evaluates the implementation of the state plan. The number for the Planning Council is **(405) 521-4984.**

## THE OKLAHOMA DISABILITY LAW CENTER

The Oklahoma Disability Law Center

The Oklahoma Disability Law Center advocates for services and promotes the rights of adults and children with mental illness who are in hospitals, jails, and other facilities as well as people with developmental disabilities regardless of where they live. They provide legal representation only to clients in these facilities at no cost when other no cost legal services are not available. The number of the Disability Law Center is **(918) 664-5883 or 1-800-226-5883.**

## UNIVERSITY AFFILIATED PROGRAM OF OKLAHOMA (UAP)

The University Affiliated Program of Oklahoma (UAP)

The UAP was approved for funding in 1991 and consists of a consortium of eight universities. UAP has commenced developing a course on developmental disabilities, conducted training programs and issued grant awards for special projects with special emphasis on direct care staff.
Additional courses are being developed. The number for the UAP is **(Okla. City) 271-4500 or 1-800-627-6827.**

***The Planning Council, the Disability Law Center, and the University Affiliated Programs are all funded through the U.S. Administration of Developmental Disabilities.***

## OKLAHOMA OFFICE OF HANDICAPPED CONCERNS (OHC)

Oklahoma Office of Handicapped Concerns (OHC)

The goal of the OHC is to further opportunities for individuals with disabilities to participate in all aspects of Oklahoma life. Some of these include:

- Promoting state government responsiveness to disability concerns.
- Linking individuals and families with needed resources.
- Promoting environments accessible to people with different disabilities.

- Advancing opportunities for employment and independent living.
- Facilitating community and state level efforts to address major disability needs.
- Helping agencies and businesses comply with laws pertaining to disabilities.

**The Oklahoma Client Assistance Program (CAP)** is located with the OHC. The CAP office handles complaints from people concerning Vocational Rehabilitation Services.

The Oklahoma Client Assistance Program (CAP)

The OHC also produces the Disability Concerns Information Network which issues bulletins covering state and federal legislation, policy issues, and other actions on key disability issues. It also publishes a bi-monthly newsletter with relevant information concerning disability issues. The number of the OHC is **(405) 521-3756 or 1-800-522-8224.**

## OFFICE OF THE GUARDIAN AD LITEM

Office of the Guardian Ad Litem

This office was established by the Court Order of December 23, 1988, to serve as advocates for Hissom class members whose parents or guardians were not actively involved with them. The number of the Office of the Guardian Ad Litem is **(918) 245-1117**.

## ■ PRIVATE ADVOCACY GROUPS

PRIVATE ADVOCACY GROUPS

The role of private advocacy groups is much the same as governmental groups; advocates support the people they serve in all areas of life. They defend and speak for those individuals with developmental disabilities who are unable to speak for themselves. Some of the advocacy groups in Oklahoma are:

- People First
- United Cerebral Palsy
- Epilepsy Foundation
- Autism Chapters
- The ARCs (formerly Associations for Retarded Citizens)

### Oklahoma Community Providers (OCP)

Oklahoma Community Providers

The OCP is a non-profit association of Oklahoma service providers throughout Oklahoma which is dedicated to protecting and enhancing the quality of life for individuals with special needs. The number for OCP is **(405) 236-1414**.

## Pro-Oklahoma (Parents Reaching Out in Oklahoma)

Pro-Oklahoma

Pro-Oklahoma provides parent training in working with schools as well as education on rights provided by the Individuals with Disabilities Education Act. The number for Pro-Oklahoma is **(405) 681-9710 or 1-800-759-4142**.

### Positive Reflections

Positive Reflections

Positive Reflections handles referrals for respite care and also schedules teen activities. The number is
**(405) 424-0045 or 1-800-357-KIDS.**

## The Tulsa Association for Retarded Citizens (TArc)

The Tulsa Association for Retarded Citizens (TArc)

TARC is an extremely active ARC organization that provides family and financial counseling, summer educational programs and information and referrals. They also provide parent support, training and respite services as well as peer support and assistance in developing and advising People First Groups (for information on People First groups, contact your area DDSD office or the TARC).
The TARC serves as an information clearing house and is a good source of literature.
The TARC number is **(918) 582-8272**.

## Oklahoma People First

Oklahoma People First

Oklahoma People First is a statewide organization of local self advocacy chapters and their members. It is a program of the Tulsa ARC. The mission of People First includes educating the community about the rights, abilities, and strengths of people with developmental disabilities, organizing and educating people with developmental disabilities and assisting each of them in speaking up for themselves, making their own decisions, and promoting equality for all person with developmental disabilities.

The National People First organization is now called Self Advocates Becoming Empowered. However, in Oklahoma, the organization is still Oklahoma People First. The number for the OPF is **(918) 582-8272.**

## INSTRUCTOR QUESTIONS

1. **List the four federal policy goals that shape the services system for people with developmental disabilities and write a brief description of each.**

2. **What four groups of people shape our service system?**

3. **What are the two main federal agencies that provide services to individuals with developmental disabilities?**

4. **Supplemental Security Income (SSI) provides a_____ for people who are ______, ________, or ________.**

5. **What is Title XIX and what does it provide?**

6. **List three programs operated by the U.S. Department of Human Services.**

7. **Who provides most of the program funding for individuals with developmental disabilities, federal, state or local agencies?**

8. **What is the role of state agencies in Oklahoma?**

9. **What is advocacy?**

10. **Who may be advocates? How involved with the lives of individuals with developmental disabilities may they get?**

11. **Why were groups formed specifically for advocacy? List two Oklahoma advocacy groups.**

***Objective 2:***

***Describe the five basic services provided by state employees and private provider agencies.***

**Objective Two**

# OVERVIEW OF RESIDENTIAL OPTIONS

**ACTIVITY** ***If possible, have someone who is currently working in Residential and Vocational Services to come and talk to the group and answer questions that they may have concerning these disciplines. As each service is discussed, also discuss who provides these services – i.e. the people involved. THIS ACTIVITY IS OPTIONAL.***

Activity: "Speakers"

**HANDOUT** ***Handouts 3A.1 - 3A.4 (DHS Services)***

Handouts 3A.1 - 3A.4 (DHS Services)

**PRESENT** Services currently offered to people with developmental disabilities generally fall into one of five broad categories: residential, educational, vocational, case management, and support services. As noted in the previous section, education is provided by the schools in Oklahoma. While not much has been said thus far about adult education, many states have increasingly involved community colleges and vocational/technical schools in developing classes for adults and children with developmental disabilities.

# RESIDENTIAL SERVICES

RESIDENTIAL SERVICES

**Residential services** are those services which assist individuals to live either in their own homes or in other arrangements. These services can be modified to meet the varying needs of individuals with developmental disabilities. All residential services, except for the resource centers at Enid and Pauls Valley, are provided through contract with private service providers.

# CONTINUUMS

CONTINUUMS

In the past, it was common for states to develop new alternatives based on the concept of a "continuum;" that is, a range of residential options from more restrictive to less restrictive. They were set up in relation to how well the person was integrated in or segregated from his or her home community.

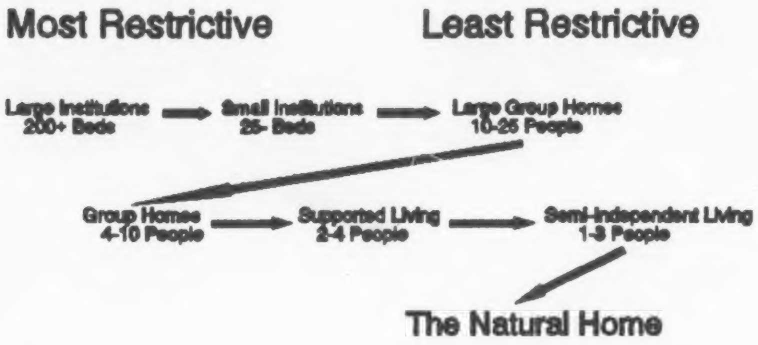
**SHOW** ***Transparency 3.11***

Transparency 3.11
(Continuums)

***Discuss the concept of continuums and how they came about. Explain:***

- ***Why the idea of a continuum is not needed; that this is not just rhetoric we are trying to pursue. Continuums suggest that before a person can advance to another level, he or she must complete "lower" levels.***
- ***What is the biggest problem of continuums?***
- ***What is meant by the statement "continuums legitimize the use of large, segregated environments as 'necessary?'"***
- ***Have the group come up with ideas about what is meant by an "array" of services.***

The trouble with the concept of continuums was that people conceptualized individuals as moving from one point to the next in a lock-step fashion across the continuum instead of assuming that everyone originally came from ordinary housing and has a right to live in such settings. Continuums also legitimize the use of large, segregated environments as "necessary." In fact, our experience has shown that, given adequate supports, virtually everyone can live in normal homes. People with developmental disabilities should not have to "earn" their way from one residential model to the next. It is the responsibility of those of us who serve individuals with disabilities to create environments that will meet their needs. Therefore, today in Oklahoma, we talk about an array of services rather than a continuum.


Most Restrictive
Least Restrictive
Large Institutions 200+ Beds
Small Institutions 25- Beds
Large Group Homes 10-25 People
Group Homes 4-10 People
Supported Living 2-4 People
Semi-Independent Living 1-3 People
The Natural Home

Cost

**The biggest problems with continuums is cost.** That is, the number of buildings that get constructed are limited only by the number of models that one can conceptualize. Using an individualized approach and existing housing, on the other hand, avoids the duplication and high cost of constructing new buildings every time we have a different group of people with disabilities (this is what some people have called the "edifices" complex).

BEST COPY AVAILABLE

## The Procrustes Myth

The Procrustes Myth

In greek mythology, there was an overly friendly character by the name of Procrustes. He wanted very much to be a good host to weary wayfarers, and when a traveler journeyed past his dwelling, Procrustes would insist that he stay the night with him. After some wining and dining, Procrustes would show his guest to his/her bed. Trouble was, there was only one bed, of one certain size, and Procrustes was a perfectionist. The bed just had to fit the guest. So, if the guest was tall, Procrustes chopped off his legs until guest and bed were exactly the same size. If the guest was too short, the host strapped him into a rack and lengthened him out a few inches. Obviously, by doing things his own way, Procrustes was prepared for all comers.

In the past, we have been Procrustean in nature. We took everyone, no matter what the disability or its severity. We took them in groups of hundreds and thousands. We used the same kinds of facilities, same types of treatments, same groups of personnel -- it didn't matter.

**If the guest didn't fit, we made him/her fit!**

But, as the old song says: "the times, they are a changing...!" We are tailoring our services to the individual instead of becoming descendants of Procrustes. We are not locked into old methods -- we are not locked into sameness. We believe that the system should be an individualized service system, an "Individual-Up" service system.

## INDIVIDUAL-UP Service Systems

Individual-Up Service System

Individual-Up Service Systems will insure that no one is denied services because of the severity of the disability or the inability of the agency to serve their needs. At one time, people were "fitted" into existing programs. In the future, we will increasingly tailor a program to fit the unique needs of the individual.

**Oklahoma is moving toward a "Individual-Up" service system** but you should be aware that there are some labels associated with residential options that identify services. **The labels for types of residential services are somewhat artificial and tend to promote fitting a person to a program rather than fitting the program to the person. In practice, even with these labels we can design a program that fits the person. And, that is what we want to do.**

# TYPES OF RESIDENTIAL SERVICES

RESIDENTIAL SERVICES

**SHOW** ***Transparency 3.12 (Residential Services)***

Transparency 3.12 (Residential Services)

Assisted Living

- **Assisted Living**. A residential setting in which the person lives in his or her own home and receives habilitation services. The level of support may vary from intensive to occasional depending on the need of the individual. The person may live alone, or roommates may choose to live together.

Supported Living

- **Supported living**. A residential program which provides state support for some living expenses in addition to staff support. Supported Living is available only to those individuals determined to be members of the Hissom Class. Supported living allows classmembers to live in their own homes, usually with one or two roommates of their choice. Personal needs such as living expenses and medical care beyond the consumer's fiscal resources are provided through this program.

- **Habilitation Services** - Services whose goal of habilitation training is to teach and assist people in carrying out everyday tasks associated with self-care, daily living, and self support. These services may include assisting individuals to following ongoing programs in physical, occupational, and speech therapies. A habilitation training specialist may also be required to implement portions of a prescribed behavior plan.

Habilitation Services

- **Adult Companion**. This is a residential option in which an adult consumer shares a home with a companion who is not a service recipient. The companion may provide support services to the consumer depending upon the companion's qualifications and the recommendations of the individual's IDT.

Adult Companion

- **Foster Care**. A living arrangement which provides an opportunity for a school-aged consumer to live in a family environment. This program encourages the reuniting of the individual with his/her natural family.

Foster Care

- **Group Home**. A residential option which provides consumers a small home-like setting in which their residence is owned or leased by the service provider rather than by the consumers. Group homes generally provide a more supervised setting. These homes are licensed by the State Health Department. Residents are encouraged and assisted in increasing their independence in areas that will allow them to care for a home and access their community for work and recreation.

Group Home

- **Resource Centers.** Large, public ICFs/MR's housing 200+ individuals with mental retardation which offer services in a supervised setting. These were formerly known as state schools

Resource Centers

- **Nursing Homes (ICFs, ICFs/MR).** Nursing homes may range from 200+ bed facilities to smaller settings that offer medical services as well as living arrangements for individuals with developmental disabilities as well as a broad range of other individuals including the elderly. In Oklahoma, more people with developmental disabilities are served in private ICFs/MR's than in all other residential options.

Nursing Homes (ICFs, ICFs/MR)

# IN-HOME AND OUT-OF-HOME SERVICES

IN-HOME/OUT-OF-HOME SERVICES

**SHOW** ***Transparency 3.13 (In-Home,Out-of-Home)***

Transparency 3.13 (In-Home, Out-Of-Home Services)

***Discuss the following outline in greater detail - defining in-home and out-of-home services and examining these with the group at large. Split the group into two smaller groups. Have the first group write down examples of what they think are in-home services and the second group list out-of-home services. Compare these and see if their ideas are consistent with what actually are in-home and out-of-home services.***

Another way to think of these services is **In-Home** and **Out-Of-Home** services. A brief outline of these follows:

A. Supporting People in Their Own Homes
  1. Within the Natural Home
    a. Children with Natural or Adoptive Parents
    b. Living alone with or without a partner(s)
  2. Adults Living Alone or with Partner(s)
    a. In a house, apartment, condo or duplex
    b. Rented, owned or leased (person with developmental disability may own or lease their own home or they may live in a residence owned by someone else)

B. Foster Homes
   1. Children's foster homes
   2. Adult homes (called "Adult Companion" homes) - 1-2 adults living with non-disabled adults

**The services provided by the above are:**

**A. In-Home Services include:**
   1. Respite (in and out of home)
   2. Meals on Wheels - for adults with very severe handicaps who live in their own homes
   3. Architectural Modification - for accessibility
   4. Visiting Nurse
   5. Community Recreation
   6. Professional Support - psychologists, physical therapists, speech therapists, occupational therapists, etc.
   7. Transportation
   8. Habilitation Staff - personnel funded by Title XIX to provide training and support as needed to the person with developmental disabilities in the home
   9. Supported Living - 1-3 persons managed by a provider whose lease on their home may be in their own name
   10. Assisted Living

**B. Out-Of-Home Services provided include:**
   1. Group Homes - 4-15 individuals
   2. Institutions - resource centers
   3. Nursing Homes
   4. Large, Private ICFs/MR - institutions
   5. Foster Care
   6. Adult Companion (may be in own home or companion's home)

**C. Services shared by both In-Home and Out-of-Home**
   1. Respite
   2. Architectural Modification
   3. Visiting Nurse
   4. Community Recreation
   5. Professional Support
   6. Transportation

**People can be supported in living settings in normal homes.** In some cases, for a variety of reasons, it has been necessary for them to live outside their own home.

## RESIDENTIAL SERVICES EMPLOYEES

It needs to be pointed out that residential services employees are often the unsung heroes, the backbone of our service system. These are people who work on holidays, weekends, at night -- when the rest of us are at home. The are often required to make decisions on the spot, they may have to work alone, and they sometimes have to meet the most basic human needs of a person with disabilities.

They help people who cannot eat without assistance, those who have toileting needs, and those who may need assistance with communication and walking, bathing, or self-care.

Residential service employees deserve the respect and support of all of us who have other jobs in the Oklahoma system and should be given as much help as possible to enable them to do their jobs.

**SHOW**

***Video "Choices"***

***Discuss:***

- ***What residential options were presented in the video.***
- ***How they represent "designing the program to fit the individual."***
- ***Be sure to make participants aware that this video was produced to provide parents with children leaving Hissom an idea of the residential options available to them. Therefore, not all options such as ICFs/MR are shown.***

Video: "Choices"

# VOCATIONAL SERVICES

VOCATIONAL SERVICES

**Vocational services** are those services which assist the individual to engage in employment or employment-related activities during the day. There are currently two options available for individuals in need of vocational services; traditional sheltered workshop or integrated employment in the regular labor market. (Integrated work places are those in which people with and without disabilities work along side each other.) All of the department's vocational services are delivered through contract with private service providers.

Just as the continuum approach of people earning their way from more restrictive and segregated environments to less restrictive integrated environments was used in the past in residential services, vocational services followed a continuum as well. With the current trend toward supporting people in real work environments in business and industry, the number of segregated, congregate employment settings will decline.

Integrated Employment

- **Integrated Employment**. Integrated employment is a term which covers a broad range of activities funded through various program areas, including Medicaid and the Developmental Disabilities Services and Rehabilitation Services Divisions of DHS. Activities include evaluation, training, job development, job placement, job assistance and paid employment. These services provide necessary supports to place consumers on jobs in the regular labor market working along side persons without disabilities.

Sheltered Employment

- **Sheltered Employment**. This service provides training and employment opportunities for persons with disabilities in a protected environment. Wages received are generally in accordance with a Department of Labor approved piece rate system based on a person's individual rate of production. (The principal activities of many workshops are the production of simple items for which the individual is paid on a per piece basis as well as on-going community integrated employment training.)

***Briefly describe other types of work situations; i.e., enclaves, work crews, etc., that may fall between the two types of situations described above.***

**SHOW** ***Transparency 3.14 (Vocational/Case Management)***

Transparency 3.14 (Vocational/ Case Management)

# CASE MANAGEMENT

CASE MANAGEMENT

Case managers in Oklahoma are state employees (although some states use private agencies to provide these services). The concept of case management was first brought forward in the late sixties, when deinstitutionalization and community development began. A case manager was to be the one person in the lives of children and adults with developmental disabilities and their families who would never say "That's not in my job description," or "I don't work those hours," or "I don't do floors and windows." This was to be a person who was an expert in developmental disabilities and who worked for the consumer and their family.

It should be noted that the term "case management" is not one that most people are very happy with for several reasons:

1. Human beings are not "cases;"
2. We don't "manage" people, they manage their own lives.

But, it is a term that has been used for a long time and for now, we don't have a better one. **Perhaps you can think of a better one.**

Another way to look at case managers is to think of them as "agents." Just as famous people have press agents or talent agents who represent their interests, case managers are agents who represent the interests of people with disabilities and their families. They make sure that the person gets everything they need and are entitled to. They fill out complicated government forms. They negotiate for services with providers and their staff.

In some ways, a case manager can be like a conductor of an orchestra. They chair the IHP meeting and compile the reports submitted by team members. They monitor what was agreed to in the meeting to be sure it gets done.

**Above all, the case manager is a friend that can be counted upon in time of need.**

# SUPPORT SERVICES

SUPPORT SERVICES

**SHOW** ***Show Transparency 3.15 (Support Services)***

Transparency 3.15
(Support Services)

***Discuss the services provided and the people who provide them.***

- ***Discuss who is responsible for what.***
- ***Now might be a good time to have participants describe what services they will be providing after training. Go around the room and have each person describe what he or she believes his or her future service role to be.***
- ***Make sure participants understand that not all people need support services. This is another opportunity to help them understand that our goal is not to "fix" people or to "cure " them or to make them "normal."***
- ***It is also a time to remind everyone that it is important to not label normal life situations, e.g., calling teenage rebellion pathological when it is exhibited by a person with developmental disabilities.***

**Support Services** are those professional, therapeutic, and habilitation activities which maintain or enhance an individual's physical, emotional, and social well-being in the community. These may include physical, occupational, and speech therapies; psychological and psychiatric services; habilitation training; family training; family counseling; architectural modification; adaptive equipment; skilled nursing; and transportation.

Most people with disabilities do not need any of these services, therefore, services are provided on an individual basis in accordance with assessments of the person's need. A case manager serves as the individual's advocate and arranges for the timely delivery of any and all services the individual requires. Support services are categorized into five general areas:

- **ASSESSMENT SERVICES** determine the individual's level of performance in various areas of life, and make recommendations regarding needs, goals, objectives, and activities to improve functioning. Specialized assessments are performed by all members of the Interdisciplinary Team, including various professionals and direct contact staff.

Assessment Services

- **COMMUNICATION SERVICES** improve receptive and expressive communication. These services may include activities to improve verbal or manual communication, provision of language boards, vocabulary packs, or electronic augmentative communication devices, as well as training in the use of these systems.

Communication Services

- **SKILL DEVELOPMENT SERVICES** enable the individual to become more self-reliant in the performance of all daily living activities, including self-care and leisure activities.

Skill Development Services

- **BEHAVIORAL SUPPORT SERVICES** enable the individual to interact positively with others in

Behavioral Support Services

his or her home, work, and community. A few individuals who have serious problems that are harmful to themselves or others may require intensive behavioral supports. Services include behavior plan development, implementation (training, monitoring, and revision), cognitive/group treatment, and psychotherapy.

Health Care Services

- **HEALTH CARE SERVICES** cover a variety of activities to improve and maintain the individual's health status including:

**Skilled Nursing Services** include preventive and rehabilitative procedures prescribed by a physician.

**Dental Services** include examination, x-rays, prophylaxis, fluoride treatment, development of a plan of care, and routine training of the individual and/or primary caregiver regarding oral hygiene.

**Nutritional Services** maximize the individual's nutritional health through consultation with a licensed dietitian.

**Psychiatric Services** enable the person to interact positively with others and may include psychotherapy, medication prescription and management, and consultation.

**Hearing Treatment** and consultation as well as

**Oral-motor activities** and eating skills

Accessibility

- **ACCESSIBILITY** to all necessary environments and activities is provided through a number of interventions:

**Architectural Modifications** can be made to the individual's existing residence to enhance use by the person and/or place of work. Such modifications are limited to items which have no utility apart from the needs of the service recipient.

**Assistive Technology** enables the individual to perform daily living skills, socialization, and/or work with reduced reliance on others. Maintenance, repair, and customization of equipment are provided.

Mobility Services

**Mobility Services** improve the individual's locomotion or mobility and are provided by, or under the supervision of, a licensed physical therapist. Skeletal and muscular conditioning can be included in this service.

Transportation Services

**Transportation** is provided to programs necessary to enhance the individual's community living skills and integration. Transportation is provided to and from medical appointments (except as provided under the State's Medicaid Plan), recreational activities, and other community activities.

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## INSTRUCTOR QUESTIONS

**12. What is a continuum? What are the biggest problems with continuums?**

**13. What is meant by "an array of services?"**

**14. What is meant by "an Individual-Up" service system?**

**15. List four types of residential services and describe how they represent designing the program to fit the individual.**

**16. Define the following terms and give two examples of each:**
**In-home services**
**Out-of-home services**
**Shared services**

**17. Vocational services are those services that assist the individual to engage in ________________________ during the day.**

**18. What is a case manager and what is his or her primary role?**

**19. List five support services and discuss what they involve.**

## *Objective Three:*

***Describe the primary way services are provided in Oklahoma.***

***This section provides a good opportunity to allow participants to explore their prior conceptions of how the different kinds of services discussed up until now are organized and coordinated. Before presenting the following material, ask participants to think about the following items:***

- ***What is an IHP? An IPP? An IDTP? An IEP?***
- ***What should go in an IHP?***
- ***What purpose does an IEP serve?***
- ***What do they think about the proposal that all children, not just those with disabilities, have IEP's?***
- ***Who composes a "Team?" What is their purpose?***

# HOW SERVICES ARE PROVIDED

# THE INDIVIDUAL PLAN

THE INDIVIDUAL PLAN

The Individual Plan is a blueprint developed by the person with disabilities and others. It is a very individualized roadmap that starts by asking the person/guardian/family what he/she wants and needs. Then, the people in the person's life come together to think of creative ways of getting to the outlined destination.

Names

By the way, there are many different names for these plans. In schools, they're called *Individual Education Plans (IEP's)*. Some call them *Individualized Program Plans (IPP's)*. In Oklahoma's Developmental Disabilities System they're called *Individual Habilitation Plans (IHP's)*. The word "habilitation" is used rather than the more common term "rehabilitation" because, unlike others with disabilities, for example war veterans or people who have strokes, the skills of people with developmental disabilities may have never been established and therefore cannot be re-habilitated, or brought back.

Behind all the mystery of these acronyms is a simple effort to bring together people who can help develop the roadmap.

Control The Environment

Consideration is thus given not only to what we intentionally plan and put into action, but also to environmental factors, such as the world of work, the school, the community resources which may or may not be available. **The person being served is affected by and affects others. The team members and the person being served should try to create a physical and social environment which will both enhance the abilities of a person and allow that person to control the environment as much as possible.**

For example, let's say we are concerned about conveying an adult image, maximizing social integration, as well as supporting the least restrictive alternative as a community living arrangement. We would then strive to provide as many concrete experiences as possible to overcome other people's perception of disability.

We would rely on things that everyone can recognize and identify with -- shopping with credit cards, living in an apartment, eating out in restaurants, joining social or church clubs, being at events, wearing tasteful, age-appropriate clothes. If the person had a physical handicap, we would use the most innovative wheelchair system. In short, we would make every effort to get persons who have developmental disabilities where the action is in a positive and enhancing way. The person would not be left at home to watch TV because it was inconvenient to get them ready to go out. Neither would they be dressed in a way that made them stand out like a sore thumb when they did go out.

***Objective 4:***
***List five different people who may be on an interdisciplinary team. Discuss their common goals.***

***Objective Four***

# WHO PARTICIPATES IN THE PLAN?

WHO PARTICIPATES?

## ■ *THE INTERDISCIPLINARY TEAM*

THE INTERDISCIPLINARY TEAM

The **Interdisciplinary Team** is a group of people who work together to develop and carry out a comprehensive plan for providing services to an individual. Their common goal is to help the individual with developmental disabilities reach whatever objectives the person with disabilities and/or family have defined as important to them.

As the term, **interdisciplinary**, suggests, the Interdisciplinary team is a coming together of several disciplines. This approach helps the team to look at the whole person, not just at one dimension (physical, social, work, etc.) of the person. Once decisions have been made and the overall program has been written, people are responsible for carrying out specific parts of the plan and the case manager works with them to coordinate their efforts.

## TEAM COMPOSITION

Team Composition

The members of the team may represent a wide variety of professions and backgrounds. The needs of people with developmental disabilities cross over professional boundaries. Only those people who are needed to help accomplish the person's goals need to be on the team, so its makeup will vary over time.

Case manager and others

The **case manager** assists the individual and\or his/her family determine who should be invited to be on the IDT. **The team's composition may include the parents or guardian and brothers and sisters, residential and vocational staff (or school teachers and aides), the case manager, and various professionals (psychologist, speech therapist, physical therapist, etc.) as needed. It may also include friends, neighbors, a van driver, or anyone who it is felt could contribute.**

The most important member

***The most important member of the team is the individual with developmental disabilities.*** The composition of the team is based on his or her individual needs and may change as that person's needs change. All team members should know the individual and those who spend time with the person every day are key sources of information and should certainly be included.

TRAINER NOTES

***Emphasize "The most important member of the team is the individual with developmental disabilities." Address why this important – why his or her needs shouldn't be determined by the team without input from that individual.***

**The guardian should be considered a full member of the team and invited to attend all meetings** (with meetings scheduled to make this possible). Individuals who have reached a majority age and who have not been declared incompetent should decide whether or not to involve their families. For adults who have legal guardians, the guardian should be included as a full member of the team.

***"The Exceptional Parent Blues"***

***After playing this tape, ask the participants for their reactions. Emphasize that parents know more about their children than do professionals who only see them a couple of hours (or less) a day so it is extremely important to really listen to what parents are saying. Use this as an opportunity to remind students about the use of jargon (such as IEP, IHP, etc.).***

Audio: "The Exceptional Parent Blues"

When formed, team members work cooperatively in developing the individual habilitation plan and in the day-to-day efforts of implementing the plan. The team operates through common agreement; each member is encouraged to offer his or her ideas and suggestions on any part of the IHP.

***Objective 5:***

***Recognize three elements of a successful habilitation program.***

***Objective Five***

# ELEMENTS OF A GOOD PROGRAM

## SHOW

***Transparency 3.16 (Elements)***

Transparency 3.16 (Elements)

***Before discussing this section, have the group list on a piece of paper the things they feel should make up a good program and individual plan. Then, show the transparency and discuss the following points, allowing for group discussion as you cover the items that will be included on their lists. List these on your flip chart as you reach a group consensus on what constitute good elements of an individual plan.***

Some things are basic when developing good programs to help people. Glasses, hearing aids, mobility equipment, and the like must be provided when needed. Consideration should be given to the design of these devices. Attention to appearance will eradicate many obvious aspects that marks a person unfavorably and consequently, help reduce social stigmas. But other less physical aspects of the plan may not be quite so noticeable. What makes a good program when it is finally implemented?

**First, it should communicate a sense of expectation.** If you know and believe that people with developmental disabilities can and will learn and grow, then your program should signal this attitude to both clients and others.

Other factors also influence the development of a good program.

A "WORKING" PROGRAM

# A CREATIVE "WORKING" PROGRAM

The program should be a real working program. It should be carried on by all who serve and should be functional and challenging. People with developmental disabilities have for too long been seen as fragile and less capable of learning. Why do children with special needs have shorter school days than typical children? Why do vocational service programs end at 3 p.m. or shut down for summer or Christmas vacations? Is this typical of business and industry? How can adults with disabilities work ll p.m. to 7 a.m. in business and industry? **Too often, issues such as who will provide transportation become major obstacles to people with disabilities.**

MAXIMUM CHALLENGE

# MAXIMUM CHALLENGE

Maximum challenge and demand must exist. Being "on the move" should be the spirit of the program -- movement from more to less supervision, from more to less support, movement from dependence to interdependence, from segregation to integration to inclusion. Programs should innovate wherever possible.

RISK TAKING

# RISK TAKING

Reasonable risk-taking should be encouraged because risk is the heart of growth. If we deprive a person of everyday risks, we deny the core of that person's humanity. It is the ground for discovering and cultivating the power necessary to control our own life. Respecting and encouraging human development requires making risk a partner in life. Overprotecting a person says powerful things to everybody about that person.

Walking risks falling. Action risks criticism. Learning risks challenge and growth. Trying risks failing. It's worth it. It's fundamental to life. It's essential to survival in a dynamic and changing environment.

Remember, we are talking about reasonable risk. We are not talking about abdicating common sense, or giving staff an excuse to not do their jobs. Unnecessary or probable dangers can be avoided, but the line between this and overprotection must be kept in focus.

# MEASURING RESULTS

MEASURING RESULTS

Measuring results is also of vital importance. Personal growth occurs daily and should be summed up frequently in a continuous, consistent way, so that patterns of growth or non-growth can be easily identified.

Sometimes the measurement of success will be defined as "letting go." The people we serve may at some point communicate to us that they neither want nor need our continued involvement. That needs to be a possibility, if it is consistent with reasonable risk taking. Certainly, families who are getting support should always be respected when they ask us to leave them alone. The only exception to this is when there is the potential that the person with disabilities is in serious physical jeopardy.

Sometimes, it is easy to sit on an IHP team and look for numerous objectives that may or may not be essential in the lives of the people we serve. We need to discriminate between objectives that are essential to well-being and those that may be simply differences in life style or personal preferences. Our job is not to make people normal (whatever that is), to create our personal conception of the perfect human being, our image of superman or wonder woman. We need to be careful to stand back and ask ourselves: "Is this objective really important?" "Who cares?" "Is it what the person wants or are we imposing our own values on the person?"

GOOD PROGRAMS

# GOOD PROGRAMS COME FROM GOOD STAFFS

The effectiveness of any program rests in the hands of the staff. Good programs come from good staff. Good staffs require good training and orientation. Training must exist for all staff and it should be continuous. Program staff should express respectful attitudes toward each other, toward clients, visitors, and the public in all possible ways.

The appropriate staff should be working with the right clients, doing what their training and background has best prepared them to do. "Doses" of therapy don't work. Direct service staff and others need to support the work of specialists and professionals.

Human service workers should be clear about how much their backgrounds, stereotypes, and the service models they learned in college liberates or constrains clients and seek the least restrictive and most developmentally appropriate technology and techniques. For example, doctors and nurses coming to work in community services need to appreciate that their experience in a hospital or institution did not necessarily prepare them to work in dispersed, integrated community settings. Similarly, most psychologists, social workers, and others get little or no exposure to developmental disabilities in their undergraduate or graduate training.

# WE ARE THE LEARNERS

WE ARE THE LEARNERS

Finally, when we look at program, especially when it doesn't seem to be working, we must be ready to say, "it is we who are the learners." In this way we can take responsibility for the knowledge we have yet to gain, the skills we have yet to learn, and the patience to try another way. We will have to accept the challenge and responsibility for lack of progress, rather than blame the person with disabilities with demeaning comments like "she's just lazy," or "he failed in that job placement." That philosophy only serves to relieve us of our responsibility for the lack of effectiveness of the plan, and the need for us to find creative solutions. In short, **try another way** if something doesn't work out the first time, and **above all recognize that we work for the consumer, not the reverse.**

## SHOW

***Video: "A Change of Seasons"***

***Discuss what the service landscape looks like today and what we as service providers can do to aid the people we serve.***

Video:
"A Change of Seasons"

***Objective 5:***

***Discuss the process an interdisciplinary team goes through in developing an individual plan.***

# DEVELOPING THE INDIVIDUAL PLAN

DEVELOPING THE PLAN

**SHOW** ***Transparency 3.17 (Developing the Plan)***

Transparency 3.17 (Developing the Plan)

Planning works best when a team of individuals work together -- each one contributing knowledge or expertise in a particular area so that the individual's plan will consider all the person's strengths and needs. This is not a rigid process. However, there are elements one would normally explore in one's own life planning, and are therefore appropriate for the people we serve.

The three phases of IHP development are:

THREE PHASES

**I. THE PLANNING PHASE**

- Self-Assessment
- Other Assessments
- Plan Development

**II. THE IMPLEMENTATION PHASE**

- Implementation Strategies

**III. THE MONITORING PHASE**

- Review
- Monitor
- Reassessment
- Movement

Further expanded, these are:

- The "**SELF ASSESSMENT**": Gives the person's and/or guardian's perspective concerning what the person may need or want. It is completed with support from the IHP Coordinator.

- The "**CONSUMER DESIRE/LONG TERM VIEW**" (CD/LTV): Based on the Self-Assessment, it is a statement of what the person and/or guardian wants in regard to outcomes for the next three to five years. For individuals for whom we have full responsibility, it will include where, how, and with whom the person will live, work, and play.

and/or

- The "**TEAM VISION STATEMENT**": For individuals who are unable or unwilling to fully participate in developing a CD/LTV and who have no guardian or family to help develop it, then the Interdisciplinary Team will establish outcomes in the areas of living, work, and play.

## The IHP has limitations:

- we cannot anticipate all that might happen in a person's life. Besides, that is regimentation, not normalization;
- it is not a substitute for competence;
- a plan written for one setting will not always transfer to another setting. When a person moves from one setting to another, the plan should be reviewed and revised if necessary within 30 days.

**The IHP is not meant to be an exercise in paperwork. It is meant to be a process, not a paper trail.**

# SUMMARY

SUMMARY

We are moving beyond viewing people in segments that each require specialized care to viewing people as *whole* people. We have moved beyond the traditional multidisciplinary team (which tended to fragment the human into parts) toward an "interdisciplinary approach" and in some cases, even a "transdisciplinary approach" where all people who come into an individual with disabilities' life work together, share information as well as objectives. We are moving toward the recognition that no one person has all the answers and that only by sharing information and allowing other people into the decision-making process can we provide a holistic view of a person's life.

And finally, we are recognizing that we need to empower people by encouraging individual and guardian participation in services, as well as assuming a leadership role in service design and delivery.

Activity: "Non-Verbal Trust Walk"

# ACTIVITY ***"Non-Verbal Trust Walk"***

- ***Divide the group into sets of partners. Blindfold one person in each set. The other person will lead their partner around an "obstacle course" (classroom chairs, desks, etc.) using no verbal clues. Afterwards, exchange roles, reverse the path and let the other participant be led. In the large group, discuss what it felt like to be totally dependent upon another person and also discuss what it felt like not to be able to communicate.***
- ***The purpose of the exercise is not to form or develop teams as such, but to get everyone at ease with each other and to aid in making people feel "equal." Emphasize that everyone has an equally important job, residential staff are the same as professional staff. This exercise will help everyone feel dependent upon one another and will hopefully aid in eliminating feelings of traditional status differential within the group.***
- ***This exercise will also aid in giving the participants insight into a portion of the lives of individuals with developmental disabilities and develop empathy and understanding.***

## INSTRUCTOR QUESTIONS

20. What does the term "habilitation" mean?

21. Why is the IHP process used?

22. Describe briefly the IHP process.

23. What are some limitatitions of the individual plan?

24. Who is the most important member of the team and why?

25. Who are some of the members of the Interdisciplinary team? Can friends and co-workers be a part of the team?

26. List several things you feel might be good elements of a successful plan.

27. Why should environmental factors be taken into consideration when developing the individual plan?

28. If a program is not working, why should the viewpoint of "it is we who are the learners" be adopted by the IDT members?

29. List some limitations of the IHP.

30. Who are some of the members of the interdisciplinary team?

31. What is meant by a "problem-solving" process in relation to goals?

# HANDOUTS

## Module Three

3A

# Developmental Disabilities Services Division
## Glossary of Acronyms

| Acronym | Meaning | Description |
|---|---|---|
| AAMR | American Association on Mental Retardation | Group of professionals working to advance technology and treatment for people with mental retardation |
| ABR | Auditory Brainstem Response | |
| ACDD | Accreditation Council on on Services for People with Developmental Disabilities | Independent organization that certifies agencies that work with individuals with DD on pre-defined performance standards |
| ADL | Activities of Daily Living | Generally pertains to skills necessary for daily living |
| AFO | Artificial Foot Orthodics | Devises used to align or support the foot |
| APAT | Area Professional Assessment Team | Obsolete: Team of Professionals who wrote individualized programs. Replaced by community based team. |
| APS | Adult Protective Services | Oklahoma Department of Human Services Adult Advocacy Program |
| ARC | Association of Retarded Citizens | A self-advocacy group for people with mental retardation and their families |
| BMC | Behavioral Management Committee | |
| BRC | Behavior Review Committee | A group of professionals who review behavior management plans for content, programs and accuracy |
| CAC | Consumer Advocacy Committee | |
| CCP | Crippled Children's Program | Program to provide medical services to children under 21 who are deprived of sufficient parental support according to DHS standards |
| CIE | Community Integrated Employment | An employment model used to assist people with mental retardation in securing work in the community |
| CM | Case Manager | The person responsible for monitoring services of the consumer of Home and Community Based Waivered Services. |

## Developmental Disabilities Services Division
## Glossary of Acronyms

| Acronym | Meaning | Description |
|---|---|---|
| CMH | Community Mental Health | |
| CMHB | Community Mental Health Board | |
| CP | Cerebral Palsy | Bilateral, symmetrical, non-progressive paralysis resulting from developmental defects in the brain or trauma at birth |
| CPR | Cardiopulmonary Resuscitation | Rescue Breathing used to provide oxygen quickly to the brain, heart and other vital organs until appropriate, definitive medical treatment can restore normal heart and pulmonary function |
| CWS | Child Welfare Services | Department of Human Services Children's Advocacy Agency |
| DCT | Direct Contact Training | Curriculum of skills training required for all paraprofessionals who work with people with mental retardation |
| DCYS | Division of Children and Youth Services | DHS division which advocates for and meets the needs of eligible children and youth |
| DD | Developmental Disability | A disability which the onset occurs during the developmental phases of life |
| DDSD | Developmental Disabilities Services Division | Agency of the Oklahoma Department Services who serve people with mental retardation |
| DHS | Department of Human Services | Division of Oklahoma state government that serve people with varying needs |
| DOB | Date of Birth | Month, day and year a person was born |
| DOE | Date of Exam | Month, day and year an examination was conducted |
| DMH | Department of Mental Health | Division of Oklahoma state government that serve people with mental illness |

## Developmental Disabilities Services Division
## Glossary of Acronyms

| Acronym | Meaning | Description |
|---|---|---|
| DPH | Department of Public Health | |
| EMH | Educable Mentally Handicapped | |
| ESS | Enid State School | Oklahoma school for people with mental retardation. Now named Northern Oklahoma Resource Center at Enid. |
| ETS | Employment Training Specialist | A person who has completed job coach training who trains and assists consumers at the job site |
| EVAL | Evaluation | A test or assessment of strength and needs |
| FAS | Fetal Alcohol Syndrome | A complex of birth defects that occur in infants born to mothers that have used alcohol during their pregnancy |
| FC | Foster Care | Care of children under 18 in DHS approved home |
| FGP | Foster Grandparent Program | Federally funded volunteer program for low income senior citizens who serve children with developmental disabilities |
| FCS | Foster Care Specialist | |
| HRC | Human Rights Committee | A group of individuals who monitor activities of agencies and individuals for human rights restrictions or violations |
| HTS | Habilitation Training Specialist | An individual who provides training to individuals with developmental disabilities in the area of daily living skills |
| ICF | Intermediate Care Facility | A long term continuous care facility for aged or disabled individuals |
| ICF/MR | Intermediate Care Facility for the Mentally Retarded | A long term continuous care facility which provides services to individuals with mental retardation |

## Developmental Disabilities Services Division
## Glossary of Acronyms

| Acronym | Meaning | Description |
|---|---|---|
| IDT or IT | Interdisciplinary Team | A group of professionals, paraprofessionals, friends, family members and individuals served who meet as needed to develop programming and an advocacy model |
| IEP | Individual Educational Plan | A program designed by a team to meet the educational needs of an individual |
| IHP | Individual Habilitation Plan | A program of service which includes goals, objectives and outcomes designed to enhance the quality of life for individuals with developmental disabilities |
| IP | Implementation Plan | A program plan which may include training, therapy or other services provided on a consistent basis which include evaluation criteria for measuring anticipated progress |
| ISD | Intermediate School District | An institution which provides educational instruction to students within a local community or certain geographical areas |
| IQ | Intelligence Quotient | A numerical score derived from standardized testing which is commonly used as a predictor of an individual's capacity to functional independently within society |
| JSU | Juvenile Services Unit | Division of DHS responsible for juvenile offenders |
| LE | Lower Extremities | The lower limb including the hip, thigh, leg, ankle and foot |
| LPN | Licensed Practical Nurse | Nurse who has completed a practical nursing program, is licensed by the state to provide routine care under direction of registered nurse or physician |
| MA | Mental Age | A score given in years or months which compares an individual's chronological age with mental functioning |

## Developmental Disabilities Services Division
## Glossary of Acronyms

| Acronym | Meaning | Description |
|---|---|---|
| MAT | Medical Aid Training | Training given to individuals who administers, tracks, and monitors medications given to others |
| MD | Medical Doctor | A professional who has a Doctorate Degree in medicine or the study of the art and source of caring for those who are ill |
| MD | Muscular Dystrophy | A disease causing wasting away and atrophy of muscles |
| MEU | Medical Evaluation Unit | A division of Department of Human Services which authorizes and monitors medically related services funded through the Department |
| MH | Mental Health | The absence of mental illness |
| MI | Mental Illness | Any disorder that affects the mind or behavior. |
| MR | Mental Retardation | Below normal intellectual function that has its cause or onset during the developmental period and usually in the first five years after birth |
| MSD | Medical Services Division | Division of DHS that serves the medical needs of clients |
| NOVA | Nova University Foster Parent Training | Required training for foster parents to introduce DHS policy and procedures |
| OBMS | Ongoing Behavior Monitoring System | Tracking documentation system that determines behavior patterns and causes |
| OBRA | Omnibus Budget Reconciliation Act of 1987. | Government agency charged with responsibility for screening and placement of individuals residing in ICF's to less restrictive environments |
| OJT | On the Job Training | Learning "hands on" job skills through training provided in a true work environment |

## Developmental Disabilities Services Division
## Glossary of Acronyms

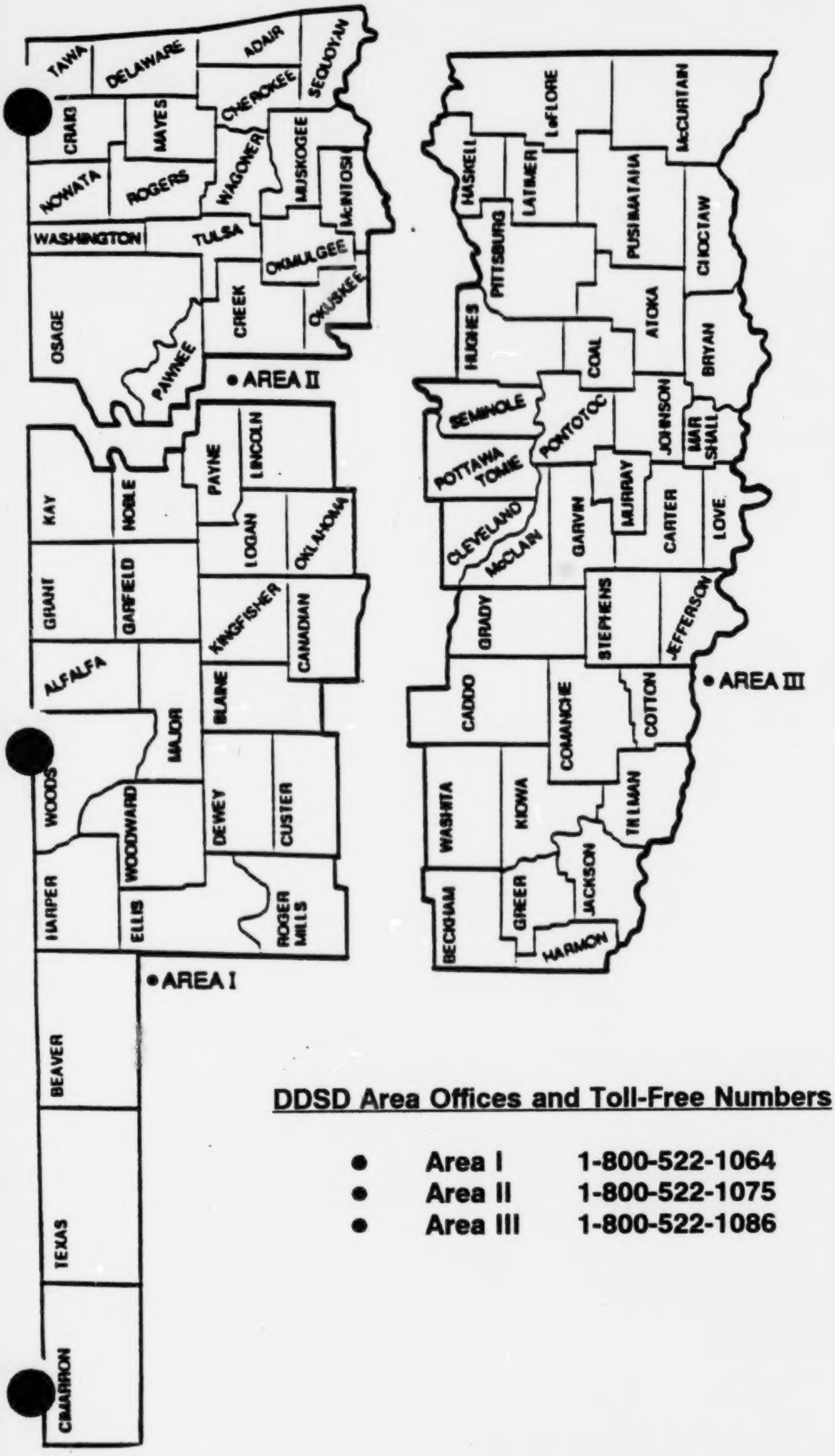
| Acronym | Meaning | Description |
|---|---|---|
| OT | Occupational Therapy | Therapeutic use of work, self care, and play activities to increase independent functions, enhance development and prevent disability; may include adaptation of task or enviornment to achieve maximum independence and to ensure quality of life |
| OT | Occupational Therapist | Individual licensed to plan, perform, and evaluate an occupational therapy program |
| PT | Physical Therapy | Treatment of disease or injury by mechanical means such as exercise, light, massage |
| PT | Physical Therapist | Individual licensed to plan, perform, and evaluate a physical therapy program |
| P & A | Protection and Advocacy Services | Independent agency that protects the rights of people with DD. |
| PS | Protective Services | See APS |
| PL-1017 | Public Law 1017 | |
| PVSS | Pauls Valley State School | Oklahoma school for people with mental retardation. Now named Southern Oklahoma Resource Center at Pauls Valley |
| QMRP | Qualified Mental Retardation Professional | A person with at least 1 year experience working directly with persons with developmental disabilities and is one of the following: MD or Osteopath, RN, OTR, COTA, RPT, CPTA, SLP, Audiologist, Professional Recreational Staff Member, Registered Dietitian, Psychologist, Rehabilitation Counselor, or a teacher |
| RC | Respite Care | Provides short term temporary services to clients to relieve the primary caregiver during absences or emergencies for both children and adults. It may be provided in a facility, the client's home or in a provider's home |

## Developmental Disabilities Services Division
## Glossary of Acronyms

| Acronym | Meaning | Description |
|---|---|---|
| RD | Resource Development | Unit of DDSD responsible for the recruitment and training of professionals and para-professionals to provide services to consumers. Also responsible for the procurement of adaptive equipment and making architectural modifications to houses (Specialized Services Unit in Area III) |
| RFP | Request for Participation | An invitation to submit application for funding to provide services to individuals needing those services in our department |
| RN | Registered Nurse | A person who has graduated from an approved school of nursing and has a license from the Oklahoma State Board of Nurse Registration that assumes responsibility of the direct care of assigned clients |
| SFC | Specialized Foster Care | Full-time care given to children (under 18) with developmental disabilities provided by an individual or family in the specialized foster care parent's home |
| SFH | Specialized Foster Home | DHS approved home for placement of children under 18 |
| SFP | Specialized Foster Parent | An individual or family with SFC and NOVA training providing care to a child with developmental disabilities |
| SIB | Self Injurious Behavior also Self Abusive Behavior | Pain or injury inflicted on oneself |
| SMI | Severely Mentally Impaired | An IQ level of 20-40 |
| SNF/MR | Skilled Nursing Facility/ Mentally Retarded | A residential facility specializing in nursing care for with mental retardation |
| SSA | Social Security Administration | The federal agency responsible for policies and regulation of social security benefits |
| SSB | Social Security Benefits | The programs available for people eligible as determined by the SSA for money to be distributed to individuals |

## Developmental Disabilities Services Division
## Glossary of Acronyms

| Acronym | Meaning | Description |
|---|---|---|
| SSI | Supplemental Security Income | |
| SSI/DCP | Supplemental Security Income/ Disabled Children's Program | Provides equipment and needs recommended by physician for SSI children that are not covered by Title XIX |
| SSN | Social Security Number | Identifying number assigned to each American citizen to track social security payments and benefits |
| TASH | The Association for Persons with Severe Handicaps | |
| THMC | The Hissom Memorial Center | Public ICF-MR in Sand Springs, OK - will be closed by 10-94 by order of Federal Judge |
| UE | Upper Extremities | The upper limb including the shoulder, arm, forearm, wrist and hand |
| VHTS | Vocational Habilitation Training Specialist | Para-professionals used to train vocation in workshop setting |
| WS | Waivered Services | Home and community-based services funded under the medical assistance program and designed to prevent or reduce the placement of persons into ICFs/MR. The services include but are not limited to case management, supervised living services, adaptive aids, homemaker services, respite care and habilitation |


OTTAWA
DELAWARE
ADAIR
SEQUOYAH
CRAIG
MAYES
CHEROKEE
NOWATA
ROGERS
WAGONER
MUSKOGEE
McINTOSH
WASHINGTON
TULSA
OKMULGEE
OSAGE
PAWNEE
CREEK
OKFUSKEE
AREA II
KAY
NOBLE
PAYNE
LINCOLN
LOGAN
OKLAHOMA
GRANT
GARFIELD
KINGFISHER
CANADIAN
ALFALFA
MAJOR
BLAINE
WOODS
WOODWARD
DEWEY
CUSTER
HARPER
ELLIS
ROGER MILLS
AREA I
BEAVER
TEXAS
CIMARRON
LeFLORE
McCURTAIN
HASKELL
LATIMER
PUSHMATAHA
CHOCTAW
PITTSBURG
HUGHES
ATOKA
COAL
BRYAN
SEMINOLE
PONTOTOC
JOHNSON
MAR SHALL
POTTAWA TOMIE
MURRAY
CLEVELAND
McCLAIN
GARVIN
CARTER
LOVE
GRADY
STEPHENS
JEFFERSON
AREA III
CADDO
COMANCHE
COTTON
WASHITA
KIOWA
TILLMAN
BECKHAM
GREER
JACKSON
HARMON

## DDSD Area Offices and Toll-Free Numbers

| | | |
|---|---|---|
| ● | **Area I** | **1-800-522-1064** |
| ● | **Area II** | **1-800-522-1075** |
| ● | **Area III** | **1-800-522-1086** |

# RESOURCE DIRECTORY

**DDS AREA I** 1-800-522-1064
**AREA II** 1-800-522-1075
**AREA III** 1-800-522-1086

**ABUSE/NEGLECT** 1-800-522-3511

**CAPITOL STRAIGHT LINE** 1-800-522-8555
**TDD (OKLAHOMA CITY)** 405-521-1602
**TOLL-FREE TDD** 1-800-522-8556

**OASIS** 1-800-246-2747 OR 405-271-6302

**OFFICE OF CLIENT ADVOCACY** 405-521-3491

**SOCIAL SECURITY ADMINISTRATION** 1-800-772-1213

**VETERANS ADMINISTRATION** 1-800-827-2206

## DEPARTMENT OF HUMAN SERVICES COUNTY OFFICES

| County | City | County Office | County | City | County Office |
|---|---|---|---|---|---|
| ADAIR | STILWELL | 918-696-7736 | LOVE | MARIETTA | 405-276-3383 |
| ALFALFA | CHEROKEE | 405-596-3335 | McCLAIN | PURCELL | 405-527-6511 |
| ATOKA | ATOKA | 405-889-3394 | McCURTAIN | IDABEL | 405-286-6581 |
| BEAVER | BEAVER | 405-625-3441 | McINTOSH | EUFALA | 918-689-2524 |
| BECKHAM | SAYRE | 405-928-3348 | MAJOR | FAIRVIEW | 405-227-3759 |
| BLAINE | WATONGA | 405-623-5282 | MARSHALL | MADILL | 405-795-7361 |
| BRYAN | DURANT | 405-924-1866 | MAYES | PRYOR | 918-825-4535 |
| CADDO | ANADARKO | 405-247-6621 | MURRAY | SULPHUR | 405-622-2186 |
| CANADIAN | EL RENO | 405-262-2030 | MUSKOGEE | MUSKOGEE | 918-684-5300 |
| CARTER | ARDMORE | 405-223-6920 | NOBLE | PERRY | 405-336-5581 |
| CHEROKEE | TAHLEQUAH | 918-456-0637 | NOWATA | NOWATA | 918-273-2327 |
| CHOCTAW | HUGO | 405-326-3325 | OKFUSKEE | OKEMAH | 918-623-1363 |
| CIMARRON | BOISE CITY | 405-544-2512 | OKLAHOMA "A" | SW OKC | 405-631-8248 |
| CLEVELAND | NORMAN | 405-321-1434 | OKLAHOMA "B" | SE OKC | 405-732-1090 |
| COAL | COALGATE | 405-927-2370 | OKLAHOMA "C" | CENTRAL OKC | 405-424-5818 |
| COMANCHE | LAWTON | 405-248-8600 | OKLAHOMA "E" | OTH | 405-271-3325 |
| COTTON | WALTERS | 405-875-6131 | OKMULGEE | OKMULGEE | 918-756-3363 |
| CRAIG | VINITA | 918-256-8711 | OSAGE | PAWHUSKA | 918-287-2956 |
| CREEK | SAPULPA | 918-224-0213 | OTTAWA | MIAMI | 918-542-1870 |
| CUSTER | CLINTON | 405-323-3333 | PAWNEE | PAWNEE | 918-762-3606 |
| DELAWARE | JAY | 918-253-4213 | PAYNE | STILLWATER | 405-372-1941 |
| DEWEY | TALOGA | 405-328-5546 | PITTSBURG | McALESTER | 918-423-3066 |
| ELLIS | ARNETT | 405-885-7546 | PONTOTOC | ADA | 405-332-1070 |
| GARFIELD | ENID | 405-233-0234 | POTTAWATOMIE | SHAWNEE | 405-275-8630 |
| GARVIN | PAULS VALLEY | 405-238-6461 | PUSHMATAHA | ANTLERS | 405-298-3361 |
| GRADY | CHICKASHA | 405-224-2733 | ROGER MILLS | CHEYENNE | 405-497-3393 |
| GRANT | MEDFORD | 405-395-3312 | ROGERS | CLAREMORE | 918-341-2282 |
| GREER | MANGUM | 405-782-3311 | SEMINOLE | WEWOKA | 405-257-6651 |
| HARMON | HOLLIS | 405-688-3361 | SEMINOLE | SEMINOLE | 405-382-6050 |
| HARPER | BUFFALO | 405-735-2541 | SEQUOYAH | SALLISAW | 918-775-4464 |
| HASKELL | STIGLER | 918-967-4658 | STEPHENS | DUNCAN | 405-255-7550 |
| HUGHES | HOLDENVILLE | 405-379-7231 | TEXAS | GUYMON | 405-338-8592 |
| JACKSON | ALTUS | 405-482-5812 | TILLMAN | FREDERICK | 405-335-5537 |
| JEFFERSON | WAURIKA | 405-228-3581 | TULSA "A" | DESTER CTR. | 918-560-4841 |
| JOHNSTON | TISHOMINGO | 405-371-2314 | TULSA "B" | N. PEORIA | 918-428-6304 |
| KAY | NEWKIRK | 405-362-2586 | TULSA "C" | S. HOUSTON | 918-581-2898 |
| KINGFISHER | KINGFISHER | 405-375-3867 | WAGONER | WAGONER | 918-485-4543 |
| KIOWA | HOBART | 405-726-3339 | WASHINGTON | BARTL'VILLE | 918-336-2655 |
| LATIMER | WILBURTON | 918-465-2333 | WASHITA | CORDELL | 405-832-3391 |
| LEFLORE | POTEAU | 918-647-2163 | WOODS | ALVA | 405-327-2714 |
| LINCOLN | CHANDLER | 405-258-1680 | WOODWARD | WOODWARD | 405-256-6091 |
| LOGAN | GUTHRIE | 405-282-4500 | | | |

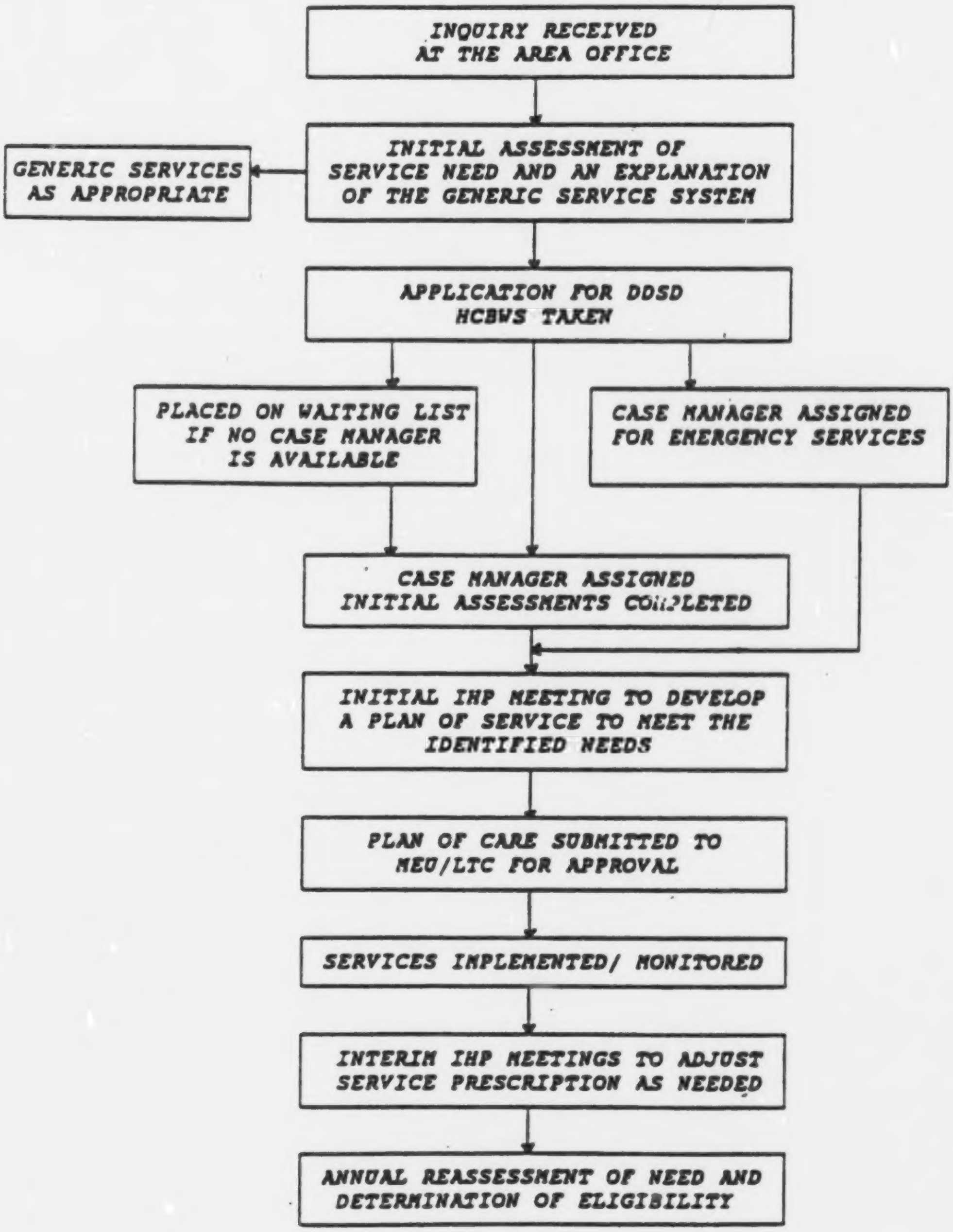
## REHABILITATION SERVICES OFFICES

| City | Office | Number |
|---|---|---|
| ADA | (College) | 405-332-0178 |
| ADA | (Field) | 405-332-2785 |
| ALTUS | | 405-482-8605 |
| ALVA | (NOSU) | 405-327-1214 |
| ARDMORE | | 405-223-6920 |
| BARTLESVILLE | | 918-336-5540 |
| CHICKASHA | (USAO) | 405-224-0709 |
| CLAREMORE | (College) | 918-341-8122 |
| CLINTON | | 405-323-3171 |
| DUNCAN | | 405-255-1115 |
| DURANT | | 405-924-2677 |
| EDMOND | (College) | 405-341-1400 |
| EDMOND | (Field) | 405-359-8994 |
| EL RENO | | 405-262-2030 |
| ENID | | 405-233-0244 |
| FT. SUPPLY | | 405-766-2311 |
| GUYMON | | 405-338-2043 |
| HOLDENVILLE | | 405-379-7231 |
| IDABEL | | 405-286-3389 |
| LAWTON | (Field) | 405-248-8600 |
| LAWTON | (Eval. Facility) | 405-353-8300 |
| McALESTER | | 918-423-8800 |
| MIAMI | (College) | 918-542-4716 |
| MIDWEST CITY | | 405-737-4897 |
| MOORE | | 405-794-1234 |
| MUSKOGEE | | 918-683-5631 |
| NEWKIRK | | 405-362-2586 |
| NORMAN | (Field) | 405-329-6096 |
| NORMAN | (Comm. MH) | 405-360-5100 |
| NORMAN | (Griffin Hosp.) | 405-321-4880 |
| OK CITY | (OCCC) | 405-682-3649 |
| OK CITY | (OSUTB) | 405-945-3285 |
| OK CITY | (Eval. Ctr.) | 405-631-4503 |
| OK CITY | (O'Donoghue) | 405-271-5258 |
| OK CITY | (OK Supp. Emp.) | 405-631-0428 |
| OK CITY | (S. Robinson) | 405-631-0866 |
| OK CITY | (Field) | 405-424-5818 |
| OK CITY | (Cap. Hill HS) | 405-631-5188 |
| OK CITY | (NW Classen HS) | 405-942-7137 |
| OK CITY | (SW Office) | 405-631-8248 |
| OK CITY | (Star Spencer HS) | 405-771-3939 |
| OK CITY | (Northeast HS) | 405-427-8484 |
| OK CITY | (Putnam City HS) | 405-787-9264 |
| OK CITY | (SSI-SSDI) | 405-840-7770 |
| OKMULGEE | (OK State Tech) | 918-756-6435 |
| OKMULGEE | (DHS) | 918-756-6424 |
| OKMULGEE | (GNRI) | 918-756-9211 |
| POTEAU | | 918-647-8121 |
| SEMINOLE | | 405-382-6050 |
| SHAWNEE | | 405-273-9922 |
| STILLWATER | | 405-372-1995 |
| TAHLEQUAH | | 918-456-6193 |
| TULSA | | 918-581-2371 |
| TULSA | (Eval. Facility) | 918-581-2366 |
| TULSA | (N. Hale HS) | 918-835-7611 |
| TULSA | (Webster JS) | 918-446-4542 |
| TULSA | (McClain HS) | 918-425-9761 |
| VINITA | | 918-256-5509 |
| WEATHERFORD | (SWOSU) | 405-772-2808 |
| WILBURTON | (Eastern State) | 918-465-2119 |
| WOODWARD | | 405-256-6738 |

## VISUAL SERVICES

| | | |
|---|---|---|
| ADA | | 405-436-2430 |
| CHICKASHA | | 405-222-0685 |
| ENID | | 405-233-0244 |
| IDABEL | | 405-286-3789 |
| LAWTON | | 405-248-8600 |
| McALESTER | | 918-423-8800 |
| MUSKOGEE | | 918-683-2873 |
| OK CITY | (Dean McGee) | 405-271-6638 |
| OK CITY | (NE 18th) | 405-521-3723 |
| OK CITY | (S.O. Staff) | 405-424-6006 |
| OK CITY | (Eval. Center) | 405-636-0140 |
| OK CITY | (Library) | 405-521-3514 |
| STILLWATER | | 405-372-2017 |
| TULSA | (S. Houston) | 918-581-2352 |
| TULSA | (N. Peoria) | 918-428-6304 |
| VINITA | (Eastern S. Hosp.) | 918-256-5275 |
| WEATHERFORD | | 405-772-5805 |
| WOODWARD | | 405-256-6738 |

# HOME AND COMMUNITY BASED WAIVER SERVICES


INQUIRY RECEIVED AT THE AREA OFFICE
INITIAL ASSESSMENT OF SERVICE NEED AND AN EXPLANATION OF THE GENERIC SERVICE SYSTEM
GENERIC SERVICES AS APPROPRIATE
APPLICATION FOR DDSD HCBWS TAKEN
PLACED ON WAITING LIST IF NO CASE MANAGER IS AVAILABLE
CASE MANAGER ASSIGNED FOR EMERGENCY SERVICES
CASE MANAGER ASSIGNED INITIAL ASSESSMENTS COMPLETED
INITIAL IHP MEETING TO DEVELOP A PLAN OF SERVICE TO MEET THE IDENTIFIED NEEDS
PLAN OF CARE SUBMITTED TO MEU/LTC FOR APPROVAL
SERVICES IMPLEMENTED/ MONITORED
INTERIM IHP MEETINGS TO ADJUST SERVICE PRESCRIPTION AS NEEDED
ANNUAL REASSESSMENT OF NEED AND DETERMINATION OF ELIGIBILITY

3F

# MAJOR FEDERAL AND STATE FUNDING SOURCES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

## ACRONYM GUIDE

## Federal Agencies

### Departments

DHHS - United States Department of Health and Human Services
DOE - United States Department of Education
HUD - United States Department of Housing and Urban Development
USDA - United States Department of Agriculture
DOL - United States Department of Labor

### Administrations

HCFA - Health Care Financing Administration
ACF - Administration on Children and Families
SSA - Social Security Administration
ADD - Administration on Developmental Disabilities
OSERS - Office of Special Education and Rehabilitative Services

## State Agencies

### Departments

DHS - Oklahoma Department of Human Services
OUHSC - Oklahoma University Health Sciences Center
SDE - Oklahoma State Department of Education
ESC - Oklahoma Employment Security Commission
DMHAS - Oklahoma Department of Mental Health and Substance Abuse

### Divisions

DDSD - Developmental Disabilities Services Division
MSD - Medical Services Division
RSD - Rehabilitation Services Division
FSSD - Family Support Services Division
DCYFS - Division on Children, Youth and Family Services

## Programs/Benefits

ICF/MR - Intermediate Care Facility for the Mentally Retarded
HCB Waiver - Home and Community-Based Waiver
OBRA Waiver - Omnibus Budget Reconciliation Act (Nursing Home Reform) Waiver
EPSDT - Early and Periodic Screening and Diagnostic Testing
SSI - Supplemental Security Income
AFDC - Aid for Families with Dependent Children
JOBS - Job Opportunity and Basic Skills
SSBG - Social Services Block Grant
MCH - Maternal and Child Health
JTPA - Job Training Partnership Act
SSP - State Supplemental Payments

# MAJOR FEDERAL AND STATE FUNDING SOURCES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

## Generic Programs

| Federal Agency |  | State Agency |  |  |
|---|---|---|---|---|
| Department | Administration | Department | Administration | Program Benefit |
| DHHS | HCFA | DHS | MSD | [illegible] |
| DHHS | HCFA | DHS | MSD | [illegible] |
| DHHS | HCFA | DHS | MSD | [illegible] |
| DHHS | SSA |  |  | [illegible] |
| DHHS | ACF | DHS | FSSD | [illegible] |
| DHHS | ACF | DHS | FSSD | [illegible] |
| DHHS | ACF | DHS | FSSD | [illegible] |
| DHHS | ACF | DHS | FSSD | [illegible] |
| DHHS | ACF | DHS | DCYFS | [illegible] |
| DHHS | ACF | DHS | MSD | [illegible] |
| HUD |  |  |  | [illegible] |
| USDA |  | DHS | FSSD | [illegible] |
| DOL |  | ESC |  | [illegible] |
|  |  | DHS | FSSD | [illegible] |
|  |  | DMHAS |  | [illegible] |
|  |  | DMHAS |  | [illegible] |

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# MAJOR FEDERAL AND STATE FUNDING SOURCES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

## *Specialized Programs*

| Federal Agency | | State Agency | | Program Benefit |
|---|---|---|---|---|
| Department | Administration | Department | Administration | |
| DHHS | HCFA | DHS | DDSD | |
| DHHS | HCFA | DHS | MSD | |
| DHHS | HCFA | DHS | DDSD | |
| DHHS | HCFA | DHS | DDSD | |
| DHHS | ADD | DHS | DDSD | |
| DHHS | ADD | OUHSC | | |
| DHHS | ADD | | | |
| DOE | OSERS | SDE | | |
| DOE | OSERS | SDE | | |
| DOE | OSERS | DHS | RSD | |
| DOE | OSERS | DHS | RSD | |
| HUD | | | | |
| | | DHS | DDSD | |
| | | DHS | DDSD | |

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# SUPPLEMENTAL INFORMATION AND ACTIVITIES

## Module Three

# PROGRAMS & SERVICES UNDER THE DHS UMBRELLA

## For children, generally younger than 18 years

| | |
|---|---|
| DAY CARE | For eligible low-income families who need child care help and supervision while the parent is pursuing an educational program, working, is in job-related training or is seeking employment, or as part of a preventive service plan to prevent neglect, abuse or exploitation. |
| LICENSING SERVICES | Regulation of child care facilities including day care centers, family day care homes and child-placing agencies; information on licensing requirements, parent referrals and free training for caregivers. |
| FOSTER CARE | Children who can no longer live with their parents receive full-time care while parents receive social services to improve family functioning or a permanent placement is developed. |
| ADOPTION | Aid in locating adoptive homes and assistance for children whose parents can no longer care for them. Counseling and support are provided to the child and adoptive parents. |
| CHILD PROTECTIVE SERVICES | Protection for those under 18 who are reported or found to be abused, maltreated or neglected. Hot Line: 1-800-522-3511. |
| CRIPPLED CHILDREN'S SERVICES | Medical services for children which supplement the services available through Medicaid. |
| SSI-DISABLED CHILDREN'S PROGRAM | Health care and social services for disabled children under age 16 who receive federal Supplemental Security Income benefits. |
| EPSDT (Early & Periodic Screening, Diagnosis & Treatment) | Health screening and follow-up treatment for persons under age 21 who are eligible for Medicaid. |
| JUVENILE SERVICES | Services for juveniles younger than 18 with law violations and behavior problems. Intake, probation, restitution and parole services in 74 counties; parole services only in Comanche, Oklahoma and Tulsa counties. |
| RESIDENTIAL SERVICES | For juveniles in DHS custody: state group homes; specialized foster homes; contracted residential care; and state institutions for diagnosis, evaluation and treatment of youth adjudicated delinquent or in need of treatment (mental health). |

## For the aged, generally older than 64 years

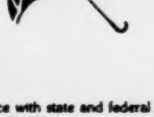
| | |
|---|---|
| ADULT PROTECTIVE SERVICES | Services for elderly or disabled adults who are reported or found to be abused, neglected or exploited and who are unable to protect themselves or their interests. Hot Line: 1-800-522-3511. |
| AGING SERVICES | Funding, administration and technical assistance for Older Americans Act programs including congregate meals, transportation, senior centers and in-home and community services. |
| LONG-TERM CARE OMBUDSMAN | Trained volunteers help receive, investigate and document complaints made by or on behalf of persons in nursing homes and other long-term care facilities. |
| NON-TECHNICAL MEDICAL CARE | Nurse-supervised in-home services by trained providers to help low-income elderly or disabled Oklahomans whose health problems would otherwise require nursing home care. |
| HOME MAINTENANCE AIDE SERVICES | Non-medical services to help improve clients' functioning at home. |
| ELDERLY ADULT DAY CARE | Respite care for persons age 60 or older during part of a day to provide social development which is not available at home and to prevent unnecessary institutionalization. |

## For blind, deaf and physically or mentally disabled persons from all age groups

| | |
|---|---|
| REHABILITATION SERVICES | Vocational, rehabilitative and visual services to help needy persons with disabilities function independently, leading to gainful employment where feasible. |
| DEVELOPMENTAL DISABILITIES SERVICES | Group homes, semi-independent living, supported living, sheltered workshops, community integrated employment and institutional services for people with developmental disabilities. |
| SCHOOLS FOR BLIND & DEAF | Residential educational programs for Oklahoma children with visual and hearing impairments. |
| OKLAHOMA LIBRARY FOR THE BLIND & PHYSICALLY HANDICAPPED | Free library services, including reading materials, disc and cassette players and radio receivers, to eligible Oklahomans whose certified disabilities make it difficult or impossible to read normal print. |
| ADULT DAY CARE | Respite care for persons under age 60 during part of a day to provide social development which is not available at home to prevent unnecessary institutionalization. |

## For financially, medically and socially needy from all age groups

| | |
|---|---|
| AFDC (Aid to Families with Dependent Children) | Cash grants for families with children deprived of support because of a parent's death, incapacity or absence; education, training and employment services; and day care assistance. |
| EMERGENCY ASSISTANCE | Limited short-term help (cash and/or services) for needy families to meet the immediate needs of children. |
| SSP (State Supplemental Payments) | State-funded supplemental cash grants for Medicaid eligibility for aged, blind and disabled Oklahomans, some of whom are not covered under the federal Social Security or Supplemental Security Income programs. |
| MEDICAID | Medical assistance for low-income people and certain others: Direct payments are made to health providers for hospital inpatient care, nursing home care and specified outpatient services provided by physicians, dentists, pharmacists and other providers. |
| FOOD STAMPS | Coupons that can be used like money to buy food, available to low-income households that meet eligibility standards. |
| ENERGY ASSISTANCE | Cash benefits to help pay home heating bills for low-income households. |
| CHILD SUPPORT ENFORCEMENT | Services to help families find absent parents, obtain child support, establish paternity and remain financially independent. Information Hot Line: 1-800-522-2922. |
| REFUGEE SERVICES | Cash and medical assistance for refugees, plus employment services, English language training and social adjustment services. |



*Note: This publication does not contain specific information on eligibility. Contact the DHS office in the county where you live to find out if you qualify for help.*

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## Questions To Consider When Thinking About Parent-Professional Collaboration

***If you are a professional:***

Ask yourself the following questions about your interactions with families. If you answer NO to any, then your next step is to develop an action plan to resolve this issue.

☐ 1. Have I ever been to their homes to meet the rest of the family and to find out what they want for the future? Do I schedule meetings when and where they are most convenient for families?

☐ 2. Do I allow for ongoing communication? Do I use a method of communication that my families like and respond to? Have I ever asked my families how they would like to keep in touch?

☐ 3. Do I spend time listening and supporting families? Would my families consider me supportive and compassionate?

☐ 4. Have I ever written off a family as uncooperative or unwilling perhaps because they don't come to "parents night" or to meetings?

☐ 5. Do families feel comfortable when they have questions or concerns to discuss with me?

☐ 6. Do I share information with them about myself when it is appropriate?

☐ 7. Do I brainstorm and share information with them about possible options for the future or the resources that are available in the community?

☐ 8. Do I allow for a time and place to help families dream of a vision for the future for their sons and daughters? Do I help then to activate their dreams?

☐ 9. Do I use jargon when I speak with families?

☐ 10. Do I focus on the strenghts of their son or daughter and plan my programs based on capabilities and not deficits and weaknesses?

☐ 11. Have I ever taken the "shoes test" and considered what it would be like for the families that I work with?

☐ 12. Would the families that I work with consider me a good collaborator? Are their suggestions taken seriously? Are they actively involved and informed about the decisions that are made?

☐ 13. Do I provide solutions and ideas that are practical, with outcomes that make sense?

☐ 14. Do I present all the options and resources when decisions need to be made?

☐ 15. How often do I negotiate for changes? Do I ever make compromises?

## IHP PROCESS

The habilitation process consist of three broad phases: the planning phase; the implementation phase; and the monitoring phase.

### THE PLANNING PHASE

The Planning Phase consists of the flowing steps:

1. Self-Assessment

   Through the Self-Assessment, the consumer and/or his family determine what outcomes they want, thus the Self-Assessment forms the basis of the IHP section entitled Consumer Desires/Long Term View. Consumer Desires/The Long Term View is a statement of where, how, and with whom the person being served will live, work, and play in the next three to five years.

2. Other Assessments

   Team members construct their assessments using the consumer Desires/Long Term View as a focus for their findings and recommendations.

3. Plan Development

   During the development of the plan, the inter disciplinary team identifies BARRIERS to attainment of the person's Consumer Desires/Long Term View. GOALS and OBJECTIVES to overcome the identified BARRIERS are developed. Time frames and team responsibilities are also identified during the planning phase.

### THE IMPLEMENTATION PHASE

IMPLEMENTATION STRATEGIES are developed to address GOALS, OBJECTIVES, and other outcomes and/or supports identified in the IHP. Often a 24 HOUR ACTIVITY SCHEDULE is used to assure that important training activities or therapies are incorporated throughout a person's day.

### THE MONITORING PHASE

All components of the individual's IHP are reviewed and monitored on a regular basis to ensure that the plan has been properly implemented and that it continues to meet the needs of the individual.

Annually the needs and desires of the individual are reassessed and the process starts over again, building on what has worked and learning from what hasn't.

The true test of the IHP process is whether or not the individual has moved towards attainment of his or her desires and Long Term View over the past year.

# INDIVIDUAL HABILITATION PLAN

NAME: CASE:

DATE(S) OF IHP MEETINGS:

## I. CONSUMER DESIRES/LONG TERM VIEW

**IDT Vision Statement:** (If necessary)

# INDIVIDUAL HABILITATION PLAN

NAME: CASE:

DATE(S) OF IHP MEETINGS:

## II. BARRIERS AND NEEDS

# INDIVIDUAL HABILITATION PLAN

NAME: CASE:
DATE(S) OF IHP MEETINGS:

## III. HABILITATION GOALS AND OBJECTIVES

**********************************************************************************

**GOAL #1 GOAL STATEMENT:**

=========================================

OBJECTIVE # 1.1

Person(s) Responsible:

DATE STARTED: DATE ENDED:
REASON ENDED:

=========================================

OBJECTIVE # 1.2

Person(s) Responsible:

DATE STARTED: DATE ENDED:
REASON ENDED:

=========================================

OBJECTIVE # 1.3

Person(s) Responsible:

DATE STARTED: DATE ENDED:
REASON ENDED:

=========================================

## INDIVIDUAL HABILITATION PLAN

NAME: CASE:
DATE(S) OF IHP MEETINGS:

*****************************************************************************************

GOAL #2 GOAL STATEMENT:

=========================================

OBJECTIVE # 2.1

Person(s) Responsible:

DATE STARTED: DATE ENDED:
REASON ENDED:

=========================================

OBJECTIVE # 2.2

Person(s) Responsible:

DATE STARTED: DATE ENDED:
REASON ENDED:

=========================================

OBJECTIVE: # 2.3

Person Responsible:

DATE STARTED: DATE ENDED:
REASON ENDED:

=========================================

# INDIVIDUAL HABILITATION PLAN

NAME: CASE:

DATE(S) OF IHP MEETINGS:

## IV. INCIDENTAL LEARNING/TEACHING

## INDIVIDUAL HABILITATION PLAN

NAME: CASE:

DATE(S) OF IHP MEETINGS:

**V. SERVICE OBJECTIVES:**

## INDIVIDUAL HABILITATION PLAN

NAME: CASE:
DATE(S) OF IHP MEETINGS:

## VI. CLIENT RIGHTS/LEGAL CONSIDERATIONS

### Understanding of Rights

### Restriction of Rights

### Review of Services

### Guardianship

# INDIVIDUAL HABILITATION PLAN

NAME: CASE:

DATE(S) OF IHP MEETINGS:

## VIII. SIGNIFICANT ISSUES

# INDIVIDUAL HABILITATION PLAN

NAME: CASE:

DATE(S) OF IHP MEETINGS:

## VIII. PARTICIPANTS

**I have participated in this meeting and agree to complete assigned responsibilities. It is the consensus of the team that this IHP recommends the most appropriate alternatives for this individual. (If a team member disagrees, he/she should attach a separate statement or explanation.)**

| Signature | Title |
|---|---|
| | |
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# INDIVIDUAL HABILITATION PLAN

NAME: CASE:

DATE(S) OF IHP MEETINGS:

Team members not attending:

* ______________________________

* ______________________________

* ______________________________

| IHP Coordinator:<br>*Signature and Title* | START DATE | END DATE |
|---|---|---|
| * ____________________ | __________ | __________ |
| * ____________________ | __________ | __________ |
| * ____________________ | __________ | __________ |

IHP Scribe:

______________________________

* Interdisciplinary Team Members

# Questions to Consider When Thinking About Parent-Professional Collaboration

***If you are a family member:***

Ask yourself the following questions about your interactions with the professionals. If you answer NO to any, then your next step is to develop an action plan to resolve this issue.

☐ 1. Do I invite professionals over to my home to discuss my child's program? Do we always meet when and where it is most convenient for professionals?

☐ 2. Do I clearly identify my dreams and visions for the future? Have I asked professionals to participate in this process?

☐ 3. Do I communicate well about what I want?

☐ 4. Do I compromise when I need to?

☐ 5. Do I assertively advocate for what I believe to be right?

☐ 6. Have I shared my child's story with professionals? Do they know about the positive contributions that my child brings to our family?

☐ 7. Have I shared with them information about past experiences, the difficult times, the nightmares?

☐ 8. Am I an active participant on the team? If I can't be, have I explained this to the professionals involved with my child?

☐ 9. Do I collaborate with professionals? Am I an active decision-maker in my child's program?

☐ 10. Do I ever compliment the professionals for doing a good job? Do I ever tell them that I appreciate their efforts?

☐ 11. Have I expressed to professionals what I am willing to participate in?

4

MODULE FOUR

# Foundation Level Training

## The New Frontiers

Department of Human Services
Developmental Disabilities
Services Division

# THE NEW FRONTIERS

## THE VISION

Module Four

# OBJECTIVES

## Module Four

# THE NEW FRONTIERS

Module 4 - Foundation Training

## LEARNING OBJECTIVES

***Primary Objective:*** Upon completion of this training and given the appropriate materials, the participant will demonstrate an understanding of future trends, both technological and environmental, influencing the delivery of services to individuals with developmental disabilities.

### *Secondary Objectives:*

- Discuss the beliefs that influence the State of Oklahoma as it provides services to individuals with developmental disabilities.
- List three areas in which the power of self-advocacy is important to individuals with developmental disablities.
- Describe the role of the State in relation to supporting families.
- List three technological advances that aid individuals with disabilities in achieving greater independence.

# Training Information And Schedules

## Module Four

# Training Schedule

## *MODULE 4 - THE NEW FRONTIERS*

| Objectives | Key Points | Exercises/ Activities | Transparencies | Handouts | Media | Length |
|---|---|---|---|---|---|---|
| 1. Discuss the beliefs that influence the State of Oklahoma as it provides services to individuals with developmental disabilities. | • Statement of beliefs<br>• Self advocacy<br>• Return on investment<br>• Individualized education | | 4.1 Statement of Beliefs | | | 30min |
| 2. List three areas in which the power of self-advocacy is important to individuals with developmental disabilities. | • Self Advocacy | "Self Advocacy Role Plays" | 4.2 Self Advocacy | 4A Speak for Themselves<br>4B Advocacy Situations | Video: "The ARC - Self Advocacy" | 1hr/30min |
| 3. Describe the role of the State in relation to supporting families. | • Supporting families<br>• Inclusion | | 4.3 Support Not Supplant<br>4.4 Matrix | | | 15min |
| 4. List three technological advances that aid individuals with disabilities in achieving greater independence. | • Technology<br>• Environment<br>• Our Task | Exercise: "Participant Menu" | 4.5 Technology<br>4.6 Our Task | 4C Enabling the Disabled<br>4D Integrated Lifestyle | Video: "Chapter One" | 1hr/30min |

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# The New Frontiers

# MODULE OUTLINE

**I. POLICIES AND TRENDS**

- A. STATEMENT OF BELIEFS
  - 1. Power Rests With Individual
- B. SELF ADVOCACY
  - 1. Beyond Special
  - 2. Power Of Self Advocacy
  - 3. Participation In Community and National Affairs
    - a. Change in perspective
    - b. Self advocacy exercise
- C. RETURN ON INVESTMENT
- D. INDIVIDUALIZED EDUCATION
  - 1. Individualized curricula
  - 2. IEP's for all students

**II. THE ROLE OF THE STATE**

- A. SUPPORTING FAMILIES
  - 1. Support, Not Supplant
  - 2. Vouchers
  - 3. Choosing Their Own Paths

- B. INCLUSION
  - 1. Full Participation
  - 2. Matrix (Movement)

**III. TECHNOLOGY AND THE ENVIONMENT**

- A. TECHNOLOGY
  - 1. Controlling The Environment
  - 2. Costs Of Technology
  - 3. Inclusion

OUTLINE - MODULE 4 (CONT.)

- B. ENVIRONMENT
  - 1. Positioning
  - 2. Positive Teaching Techniques
    - a. "Controlling" methods used in past
    - b. Non-aversive methods
    - c. New educational approaches
  - 3. Facilitated Communication
- C. OUR TASK

OUTLINE - MODULE 4 (CONT.)

B. ENVIRONMENT
  1. Positioning
  2. Positive Teaching Techniques
    a. "Controlling" methods used in past
    b. Non-aversive methods
    c. New educational approaches
  3. Facilitated Communication

C. OUR TASK

# LECTURE AND ACTIVITIES

## Module Four

# The New Frontiers

## MODULE OUTLINE

**I. POLICIES AND TRENDS . . . . . . . . . . 3**

- A. STATEMENT OF BELIEFS . . . . . . . . . . 3
- B. SELF ADVOCACY . . . . . . . . . . 5
- C. RETURN ON INVESTMENT . . . . . . . . . . 7
- D. INDIVIDUALIZED EDUCATION . . . . . . . . . . 7

**II. THE ROLE OF THE STATE . . . . . . . . . . 10**

- A. SUPPORTING FAMILIES . . . . . . . . . . 10
- B. INCLUSION . . . . . . . . . . 12

**III. TECHNOLOGY AND THE ENVIONMENT . . . . . . . . . . 15**

- A. TECHNOLOGY . . . . . . . . . . 15
- B. ENVIRONMENT . . . . . . . . . . 17
- C. OUR TASK . . . . . . . . . . 21

*"For I dipped into the future,*
*Far as human eye could see,*
*Saw the Vision of the World,*
*And all the wonders that would be..."*
Alfred, Lord Tennyson (1809-1892)

# THE NEW FRONTIERS

## The Vision for Oklahoma Tomorrow

Module 4 - Foundation Training

## INTRODUCTION

INTRODUCTION

This module will take a look at future trends that may shape the lives of people with developmental disabilities and their families. It is derived from what we know about the past -- what worked and what didn't -- and the present -- the good, the bad, and the ugly.

It is common for futurists to do what is known as "trend extrapolation," that is, to take trends and project them into the future.

What are the trends in developmental disabilities? You have already studied some of them. There has been a trend for residential and vocational services to serve people in smaller numbers, in the same settings where the rest of us live and work. There has been a trend toward greater inclusion of people with disabilities into the mainstream of society, and a trend therefore for people without disabilities to have more contact with their friends and neighbors who have disabilities.

This module will examine "The New Frontiers" based on trend extrapolation. We will study values, which are the abstract, driving force for all societal change, and we will also look at concrete developments in the area of technology. In order to be realistic, we must look at the issues of limited resources and the need to maximize our assets.

# *THE NEW FRONTIERS*

***Objective 1:***

***Discuss the beliefs that influence the the policies of the State of Oklahoma in the provision of services to individuals with developmental disabilities.***

**Objective One**

# POLICIES AND TRENDS

POLICIES AND TRENDS

## STATEMENT OF BELIEFS

STATEMENT OF BELIEFS

**SHOW** ***Transparency 4.1 (Statement of Beliefs)***

Transparency 4.1 (Statement)

***Discuss why it is important to have a set of beliefs that guide us as we deliver services to individuals with developmental disabilities.***

If this training has been successful, it has led you to embrace the following beliefs:

We, the people of Oklahoma, with a firm belief in the inalienable rights of all individuals to live full lives, do state:

✓ All individuals have the right to lead productive lives to the fullest extent possible;

✓ All individuals have the right to full participation in the decisions that concern their lives;

✓ All individuals have the right to be educated to the highest degree, and in the most typical environment, possible;

✓ All individuals have the right to their personal values without imposition or infringement;

✓ All individuals have the right to fully exercise their liberties as citizens of their community and country;

✓ All families are entitled to the integrity and well-being that comes from the firm assurance of support and entitlement;

✓ All individuals have the right to risk; to experience not only the satisfaction of achievement, but also the challenges of failure;

✓ All individuals should have their needs respected with regard for individual desires, capabilities, living situations, and medical requirements.

**Above all else, we believe power rests with the individual:** each person must be given the opportunity to develop and shape his or her own destiny in a manner that emphasizes and supports the goals he or she may strive to achieve. To that end, and with the firm knowledge of the trusts we bear, we look to the vision of Oklahoma's New Frontiers.

Power Rest With Individual

---

**INSTRUCTOR QUESTIONS**

1. Why are beliefs important?

2. Are there other beliefs that should be included in this statement?

---

## *Objective 2:*

***List three areas in which the power of self-advocacy is important to individuals with developmental disabilities.***

*Objective Two*

# SELF-ADVOCACY

SELF ADVOCACY

**SHOW** *Transparency 4.2 (Self-Advocacy)*

Transparency 4.2
(Self Advocacy)

**HANDOUT** *Handout 4A (Speak for Themselves)*

Handout 4A
(Self Advocacy)

***Discuss:***

- ***How self-advocacy differs from other types of advocacy?***
- ***Why is it important for individuals with developmental disabilities to engage in self-advocacy?***
- ***What are some of the misconceptions that the public might hold toward the individual with disabilities concerning self-advocacy?***

**PRESENT** As a state, Oklahoma is moving beyond "Special." The day will come when labels are no longer applied to people with developmental disabilities, when they are not viewed as "special" people but simply as human beings. The same as us. The same as anyone.

Beyond special

All individuals with developmental disabilities must recognize their own worth. They must be able to realize that they have the power of self-advocacy -- the power to influence their own futures. As a population, they can bring about changes in attitudes and beliefs by their very participation in community and national affairs.

Power of self advocacy

# PARTICIPATION IN COMMUNITY AND NATIONAL AFFAIRS

Participation In Community and National Affairs

## SHOW

*Video - "The ARC - Self-Advocacy"*

Video: "The Arc: Self Advocacy"

Those of us who work in the field of developmental disabilities can help give individuals with developmental disabilities an awareness of this power. We can, and should, use every effort to reinforce people's self-esteem and confidence. This in turn will lead to increased participation in those events that influence the public's awareness and perceptions.

**With awareness will come a change in perspective,** not only by the public, but also by the individual and his or her family. There will come an awareness of the things that people with disabilities can accomplish, and from that awareness will arise the ability to accomplish.

Change in perspective

## HANDOUT

*Handout 4B (Advocacy Situations)*

Handout 4B (Advocacy Situations)

## ACTIVITY

*Activity: Role Play "Self Advocacy"*

Activity: "Role Plays"

***You may break the group into smaller groups of 4-5 individuals and let them role play self-advocacy situations as given in the methods section. Afterwards, have the group discuss why the advocacy either worked or didn't work and what the benefits were from the situation if the advocacy was successful.***

> **"All people are human beings;**
> **All human beings are valuable;**
> **All the rest is commentary..."**
> **Burton Blatt**
> **"Christmas in Purgatory"**

# PRESENT

## RETURN ON INVESTMENT

Return On Investment

Having said that, we must nevertheless get away from the recurrent theme of "return on investment" -- that individuals with developmental disabilities are valuable only in relation to their ability to earn a living, and be totally independent of a need for our services. No one in this society can claim to be totally independent of others. We are all interdependent. Some people with disabilities will always be dependent upon us. They may or may not be taxpayers. But that has nothing to do with their value as human beings.

## INDIVIDUALIZED EDUCATION

Individualized Education

Individualized curricula

**Parents of children without disabilities are increasingly impressed with the power of individualized programs for kids with disabilities, and are beginning to demand the same individualization for their own sons and daughters.**

Education is more than just learning the "three R's." Education is also an environment where students learn from each other. Education leaders will be in the forefront of developing individualized curricula which allow all students, not just those with disabilities, to stretch their minds and achieve goals not thought possible in the past. Skill teaching (where prerequisite basic skills are assessed and then taught in order to master more complex behaviors) and manipulating the physical aspects of the written curriculum (using such things as font selection, colored paper, and layout to aid students with learning disabilities in reading and understanding information) are a couple of techniques that are being researched and implemented in the classrooms.

Which brings us to an important prediction -- the current Individual Education Plans (IEP's) required for children with disabilities are valuable tools. **Why not use them for all students?** Parents of children without disabilities are increasingly impressed with the power of individualized programs for students with disabilities, and are beginning to demand the same individualization for their own sons and daughters.

IEP's for all children

**Most importantly, students who go to school from the beginning with people who are diverse in terms of color, ability, religion, and other characteristics, are more likely to be comfortable with "differentness."** They know each other as human beings, not as labels. And, in adulthood, they are more likely to seek such diversity. The value of integrated education is more than the impact it has on kids with disabilities. It has a beneficial impact on the future lives of students without disabilities as well.

## INSTRUCTOR QUESTIONS

3. How does self-advocacy differ from other types of advocacy?

4. Why is it important for individuals with developmental disabilities to display self-advocacy?

5. What are some of the misconceptions that the public might hold toward the individual with disabilities concerning self-advocacy? Why?

6. Why is the term "special" unsatisfactory when discussing individuals with developmental disabilities? ("special" schools, "special" classes, "special" people?)

7. What is the "power of self-advocacy" and how can it change attitudes and beliefs?

8. How could the development of individualized curricula help students without developmental disabilities?

*Objective 3:*

***Describe the role of the State in relation to supporting families.***

**Objective Three**

# THE ROLE OF THE STATE

THE ROLE OF THE STATE

## SUPPORTING THE FAMILY

SUPPORTING FAMILIES

**SHOW** ***Transparency 4.3 (Support, Not Supplant)***

Transparency 4.3 (Support, Not Supplant)

***Use this as an introduction to the next section. Be sure to emphasize how important this concept is and how easy it is to supplant the family even though we may not mean to do this. Give examples.***

**PRESENT**

The role of the State of Oklahoma and its service providers should be defined as:

### Support, Not Supplant, the Natural Home

Support, Not Supplant

The family is the main, and best, supportive environment possible. Of course, families can be defined in many ways.

Whether traditionally (one father, one mother, and various siblings), or non-traditionally (a few friends living together and caring about each other), families provide the strength and support necessary for a person with developmental disabilities -- to achieve his or her full potential.

## Vouchers

Vouchers

**SUPPORT!**
**NOT SUPPLANT**
**the natural home.**

The least intrusive, most cost-effective and empowering method of helping people with disabilities and their families is to provide support within the family unit. Unfortunately, most support money is currently directed toward out-of-home providers. (Oklahoma has begun this process through a limited number of family support assistance payments. These are available to families earning less than $45,000 per year with children living in the home.)

## Some Thoughts...

In the past, architects would build beautiful buildings and landscape them with perfectly manicured lawns bordered with beds of flowers and shrubbery. They would then layout nice, neat perfectly straight sidewalks for people to walk on so that the grass would not be damaged. Unfortunately, people tended to ignore the nice, straight paths, choosing instead to shortcut through the grass and across the flower beds in the most direct path possible from one point to another.

Choosing Paths

Now, smart architects have changed their strategies. They build their buildings and lay out their landscape. But then they wait. They wait to see where people will walk before they put in the sidewalks. They wait to see where the paths will lead -- where people want to go.

Gone are the straight lines and precise paths.

Now, they lay sidewalks that go where people want to go.

They let people choose their own paths.

Oklahoma is also building paths. The day of continuums and models is gone. We have made mistakes in the past but we have learned from those mistakes. We have faced the risks and risen to the challenges. What we are building, we are building **one person at a time**. We won't know the final results until we have watched the paths and found where people choose to go. We won't know the final results until all we are building is completed. But we have begun.

## INCLUSION

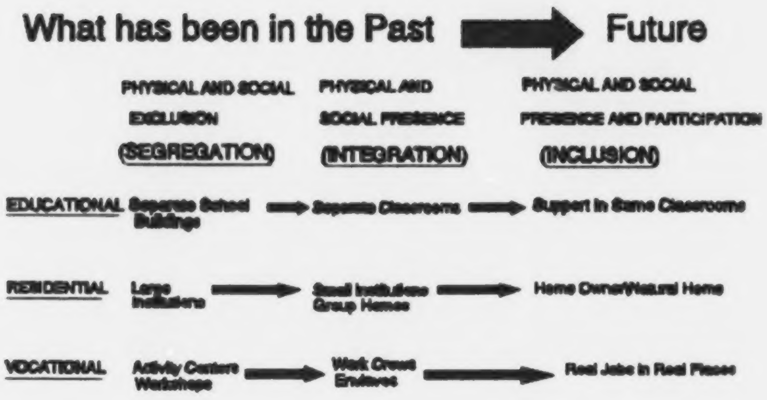
INCLUSION

***After presenting the following material on inclusion, involve the group in a discussion about presence and participation as well as how inclusion differs from integration. On a flip chart, list areas that used to be integrated but now are moving toward inclusion (example: the public school classroom).***

While integration is the presence of a person within a community, **inclusion is the presence and full participation of a person within a community**. The trend is toward movement away from large, congregate environments to more typical environments where people with developmental disabilities live in the middle of things.

Full Participation

One way to conceptualize this trend is to analyze what has been happening in the three major areas of service delivery -- education, residential, and vocational -- over the past twenty years. If we look at each of those fields, we can see that there has been a clear trend from social and physical segregation --toward social and physical presence (integration), toward social and physical presence and participation.



What has been in the Past → Future

| | PHYSICAL AND SOCIAL EXCLUSION (SEGREGATION) | | PHYSICAL AND SOCIAL PRESENCE (INTEGRATION) | | PHYSICAL AND SOCIAL PRESENCE AND PARTICIPATION (INCLUSION) |
|---|---|---|---|---|---|
| EDUCATIONAL | Separate School Buildings | → | Separate Classrooms | → | Support in Same Classrooms |
| RESIDENTIAL | Large Institutions | → | Small Institutions<br>Group Homes | → | Home Owner/Natural Home |
| VOCATIONAL | Activity Centers<br>Workshops | → | Work Crews<br>Enclaves | → | Real Jobs in Real Places |

**SHOW** *Transparency 4.4 (Matrix)*

Transparency 4.4 (Matrix)

***Discuss movement from past conditions toward future goals. Ask "Where are we today?" and "Where do we want to go?"***

# PRESENT

## SOME THOUGHTS...

Oklahoma is moving from an environment of segregation to one of awareness and participation in regards to the person with developmental disabilities. In the four areas of social, educational, residential, and vocational services as seen in the following matrix, we are striving to achieve the concepts of independence and opportunity for all people.

***Discuss how the past affects the future. Discuss how we are slowly moving away from integrated environments toward those that are comprised of inclusion. Give examples.***

## INSTRUCTOR QUESTIONS

9. **Why should Oklahoma move from state-supported institutions to family support services?**

10. **Why is the Procrustes Myth discussed earlier applicable today to individuals with developmental disabilities?**

11. **What is meant by the term "Inclusion?"**

***Objective 4:***

***List three technological advances that aid individuals with disabilities in achieving greater independence.***

***Objective Four***

# TECHNOLOGY AND THE ENVIRONMENT

TECHNOLOGY AND THE ENVIRONMENT

**HANDOUT** ***Handout 4C***

Handout 4C (Enabling The Disabled)

**SHOW** ***Video "Chapter One"***

***Point out that there are many things (glasses with captions that read on lens, computer that uses scale pressure to instruct a student, computer that takes directions through hand movement, etc.) that may be missed if not watched closely.***

Video:
"Chapter One"

## TECHNOLOGY

TECHNOLOGY

Technological advances are making available almost daily new innovations to improve the lives of people with developmental disabilities. This technological "empowerment" allows individuals to take control of their environment. Adaptive devices aid individuals in modifying existing technology to fit their unique situations. Accessibility laws also allow individuals access to all public areas.

Controlling The Environment

Costs of Technology

Although the costs of technology are high today, various groups (people who are elderly, those with physical disabilities, etc.) are combining their influence with advocacy groups for people with developmental disabilities to bring the costs of technology to a manageable level. Increased awareness and use of adaptive technologies are helping to create a business market that is increasingly competitive, which in turn helps lower costs.

Transparency 4.5 (Devices)

## SHOW

***Transparency 4.5 (Technology)***

***After you have presented this section, ask the group if they know of any other technological advances or trends that may be upcoming. List these on a flip chart.***

## PRESENT

Innovations

**Some technological innovations that may be in common use in the future include:**

- Hovercraft (wheel)chairs that will allow movement over the most rugged surfaces.
- Telephone accessory devices that relay typed messages from individuals with hearing impairments to other telephone users.
- Computer-controlled doors that respond to voice commands to open and shut.
- Glasses that allow people with hearing impairments to read what a speaker is saying on the inside of the lens.

- Talk-back computers that allow individualized education as well as open employment opportunities in a variety of fields.

**Devices that are readily available include the following:**

- Chairlifts that allow individuals to get in and out of bathtubs.

- Battery-powered, light aluminum and plastic chairs to replace heavy steel wheelchairs.

- Flexible and miniaturized communication boards and computer keyboards that allow communication of needs and feelings.

The challenge for all of these technologies -- those that are not in common use and those that are available to day -- is to make them readily available in the future.

**While some of these devices are still in the experimental design stages, many do exist.**

**Imagine what the future might bring.**

# ENVIRONMENT

ENVIRONMENT

## POSITIONING

Positioning

New "positioning" techniques allow people to maximize their control over their bodies. If people's physical body positions are not changed regularly, gravity will affect the correct functioning of many organs and structures. Bones become misshapen, organs do not function properly, and food cannot be eaten in a correct manner. The ability to grow and develop is severely diminished. New techniques of physically moving and "positioning" an individual's body can aid or eliminate many of these negative occurrences. What will happen if, in the future, we get infants early enough to prevent the deformities we now seek to minimize or reverse?

## POSITIVE TEACHING TECHNIQUES

Positive Teaching Techniques

In the past, there was a great deal of concern regarding people who displayed severe behavior problems, e.g., were destructive toward themselves or others. The methods used in the past were primarily designed to control people -- to prevent them from hurting themselves or others. Some of those methods were almost from another era (such as the Spanish inquisition). This punishment approach dehumanized both the person who used the methods and the person on whom it was used.

Controlling methods in past

**Oklahoma has committed itself to the abolition of aversive punishing approaches to change behavior. It is one of the first states in the country to do so.**

Abolition of aversive methods

## FACILITATED COMMUNICATION

Facilitated Communication

Facilitated communication is a method of facilitating expressive, symbolic communication with people who are non-verbal, or who are limited and delayed in their expressive ability. It is a method by which a person supports the hand or arm of an individual who is communicatively impaired in a manner that enables him/her to accurately press the keys of a typing device and thus to communicate.

**INSTRUCTOR QUESTIONS**

12. How does technology allow an individual with developmental disabilities to become independent? Give examples.

13. List three environmental modifications that can allow an individual with developmental disabilities become more independent.

14. How can proper positioning help an individual?

15. Discuss the development of positive teaching techniques for all children. Why would parents of "normal" children want to see the same techniques used for their children?

## SUMMARY

SUMMARY

### EXERCISE *"Participant Menu"*

Exercise: "Participant Menu"

***Ask all participants to write 3-4 questions on a piece of paper that they may have concerning the training they have been through. Break into small groups and let them discuss their questions. In the large group, bring up as many questions with their answers as time allows. Use this as a "summing up" process to the foundation training. This is an excellent opportunity to "lay it all out" and allow the participants to voice any concerns and expectations they may have concerning their future roles.***

## PRESENT

## HANDOUT *Handout 4D (Totally Integrated Lifestyle)*

Handout 4D (Totally Integrated Lifestyle)

***Discuss the handout and the trend from segregated and isolated situations to total integration within society for people with developmental disabilities.***

We are moving from segregation to inclusion.

We are moving towards supporting people in their own homes.

We are moving from " programs," "models," and "continuums," toward individualization.

In short, we are moving in directions that promote the individual, in directions that say

-- loudly and clearly --

All people are...

People!

The future is a bright vision. We are following paths whose direction promises hope and fulfillment...

For all people!

**SHOW** ***Transparency 4.6 (Our Task).***

***Go back to the introduction where we described "don't shove this information down the participants' throats" and summarize again the training at this point.***

Transparency 4.6
(Our Task)

# OUR TASK

OUR TASK

Our task each day is to give the assistance required to allow each individual to be as independent as possible.

Our task each day is to be an advocate who helps create the work, leisure and home environment which allows each individual to be as independent as possible.

Our task each day is to treat the people we work with and the people we work for with respect and dignity. Regardless of the developmental disability a person has, each one deserves the opportunity to live the fullest life possible.

Our task each day is to provide the resources for the person to accomplish the fullest life possible.

**People with developmental disabilities have more options today than they have had in the past.** However, there are still many prejudices that exist and their struggle is still very real. You as service providers can be advocates for the people you serve. You can start to tell your friends and neighbors about the great things that are happening. You can promote legislation which protects the rights of people with developmental disabilities. You can dispel some of the myths and misconceptions that still exist. You can help in so many ways.

**It all begins with respect for human dignity.**

Remember...

We are all interdependent.

We are all People First.

We can all help each other to get the most out of life!

People with disabilities must be treated as human beings...

Who have value within the community

And are valued by the community for the contributions they make.

# HANDOUTS

## Module Four

# WHAT WORKS TO HELP PEOPLE SPEAK FOR THEMSELVES TO CHANGE THEIR OWN LIVES?

A person's ability to speak for him or herself grows when others:

Firmly believe that the person has the right to choices, both in every day life and in setting life goals.

Do not label the person, but get to know the person for him or herself.

Ask and listen with care to what the person wants, what the person's goals are, what specific help the person needs.

Focus on the person's capabilities, not the person's inabilities.

Match supports to the person instead of putting the person into what's available.

Excourage the person to work on what the person wants, even if it is hard to see how far the person can go toward a goal.

Work along with the person to find ways to make what the person wants possible by helping with problem solving and by connecting the person with other people who can be trusted to help.

Realize that the person can learn from mistakes if the person has the right to make them and then support to figure out what went wrong and how to move on.

Recognize that it's O.K. for the person to say, "I hate this. Let's start over!"

# SELF-ADVOCACY

## Role Plays

**Case #1** - Samantha is 23 years old and has been blind from birth. Her friend, Johnathan, believes that Samantha should run for city council since she has a unique perspective on the treatment of individuals with developmental disabilities. However, Samantha and Johnathan have run into opposition from other council members who believe that Samantha's disability would hamper her performance of her council duties. Samantha and Johnathan must convince the council that this would in no way be a detriment and might, in reality, be an asset.

**Players:**

Samantha - self-advocate
Johnathan - advocate
2-3 council members - opposing

**Case #2** - Gary is a sixteen-year-old with moderate mental retardation. He wants to move into a group home but his parents are afraid that he cannot function in a community setting -- that he won't be protected enough. Gary is also afraid, but has talked to his case manager, Margery, and his friend, Jeff, both who are currently living in such a home. They have encouraged him and he is anxious to try such an arrangement. Gary and Margery must convince his parents that he is able to make such a move. Gary must also gain confidence enough to present his case convincingly.

**Players:**

Margery - case manager
Gary - self-advocate
2-3 family members - opposing

**Case #3** - Amy is a thirteen-year-old girl with mild mental retardation. She has been in a "special" education class at her school. She no longer wants to remain in this class and instead go to the same "regular" classes as her schoolmates. Her parents also feel that this change would be beneficial to Amy. However, one math teacher and two school board members are opposed, saying that Amy's presence would slow down the regular curriculum too much for the other students. Amy and her parents must convince these individuals that she would be able to handle the work.

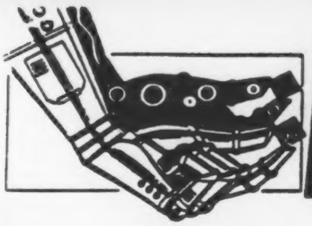
**Players:**

Amy - self-advocate
Her parent(s) - advocates
Math Teacher and two school board members - opposing

**Case #4** - Jeremy is a twenty-five-year-old man with epilepsy. His condition is fairly severe so he is currently wearing head protection for seizures. (Someday we hope to be able to use technology to discontinue use of such stigmatizing devices.) He does not want to continue to wear this since his medication has been working and he has had only mild\medium seizures perhaps once every three or four months for the last two years. His doctor and his mother do not believe Jeremy should remove his head gear, but both his case manager and his physical therapist believe that he has enough prior warning concerning the onset of a seizure that he would be able to protect himself accordingly. Jeremy and his support team must present a convincing enough case that his doctor and his mother will agree to not using the head gear.

**Players:**

Jeremy - self-advocate
Support team (2) - advocates
Physician and mother - opposing



# ENABLING DISABLED

## *Technologies for People With Handicaps*

A search for technologies to assist people with disabilities turned up a tabling mouse, flexible keyboards, and a program for creating music.

A computer engineer who has been profoundly deaf since birth found it frustrating to use the traditional telecommunications device for the deaf (TDD), since its one-line readouts are slow and cannot be stored. And he couldn't communicate with colleagues or anyone else who didn't have a TDD unless they used a telephone operator as a translator.

So Dillip Emmanuel built a better telecommunications device—one that turns a personal computer into an all-purpose communications center. His MIC300i modem and *FullTalk* software allow the user to receive, record, review, and send telephone calls through a PC. The package includes telephone directories, auto-redial functions, and other customized features, many of which promise to make it beneficial even to non-deaf users. The package could also be a boon to the many companies that hope to expand their services to deaf customers. Emmanuel now heads a company that manufactures and markets his invention.

A biomedical engineer working on brain research at the National Institute of Health wanted to create an inexpensive learning device to help his young, severely retarded son to communicate and develop thinking skills. So Andrew Mitz went down to his basement and built a simple electronic recorder and playback device—a pair of black boxes onto which he attached photographs of a toy or any other object the child might want. He named the device *WeeTalk*. Touching one of the photos activates the device to "say" the name of the object, which cues a parent or teacher to bring the desired object. Mitz found an almost instant market for *WeeTalk*, which he continues to build in his basement and now sells for $185 apiece. What Emmanuel and Mitz—and hundreds of other inventors—realized is that necessity is still the mother of invention. And for meeting the needs of the 43 million disabled persons in the United States, computers may have become the "midwife" of invention.

More than 700 ideas emerged from a recent competition for "enabling" technologies. The goal of the Johns Hopkins University Search for Computing applications to Assist Persons with Disabilities was "to apply computer creativity to help people with disabilities overcome barriers to communication, movement, education, or employment," according to Paul L. Hazan, an administrator at Johns Hopkins' Applied Physics Laboratory, who directed the project. Andrew Mitz's *WeeTalk* and Dillip Emmanuel's telecommunications modem were just two of 30 regional winners whose new enabling technologies were on display for two days at the Smithsonian Institution.

Many of the inventions were modifications that make computers easier for disabled people to use, such as the *Unicorn Smart Keyboard*, developed by Arjan S. Khalsa of Richmond, California. The Keyboard, which took top prize ($10,000) at the Johns Hopkins Search, is a flexible, affordable alternative to standard computer keyboards. It comprises 576 small keys that can be grouped to form larger, custom keys, thus simplifying the keyboard and giving access to the computer by a mere touch of the hand. The system comes with seven preprogrammed overlays to meet specific needs, such an all-alphabet overlay, all-numbers, alphabet and numbers, arrows, and standard QWERTY. With a special program, users will be able to customize their own keyboard configurations to assign a single character, word, phrase, or sequence of keystrokes to each key.

Another keyboard modification was devised by Jeffrey and William Szmanda of Menomonee Falls, Wisconsin. They broke the standard flat keyboard apart so that the pieces can be adjusted to each of the user's hands. The *Comfort Keyboard* consists of three sections: the two sides of the traditional QWERTY key-board cut in half and a third component for the numeric keypad. Each section can be adjusted into an infinite number of positions to accommodate the natural posture of each hand.

The *Comfort Keyboard* could aid people with cerebral palsy, muscular dystrophy, arthritis, or other physically impairing conditions, as well as quadriplegics who use a head wand to type on the keyboard. But the device also has promise in preventing disabilities: Many people who use computers every day suffer from carpal tunnel syndrome resulting from repetitive hand and wrist motions in awkward positions. To assist computer users who are blind, IBM programmer Frank A. McKiel of Trophy Club, Texas, came up with a "talking mouse," which generates musical tones, filtered noise, sound effects, and synthesized speech. The goal was to provide audio feedback as the user moves a pointer over windows, controls, and other graphical features on a computer. McKiel won third prize ($1,500) in the Johns Hopkins Search.

Among the many computer-based learning aids introduced was an animated program for helping hearing-impaired persons improve their speech-reading skills. "Read-My-Lips," developed by Kathleen Ahlers and Joaquin Villa of Illinois, animates any language that uses the Latin alphabet, demonstrating the positions of the lips, tongue, and vocal organs as they produce individual syllables. The interactive, multimedia instructional modules use stories and games to teach lipreading, vocalization, and other language skills for the deaf.

Hazan is optimistic about the potential impacts that these and other enabling technologies will have on the lives of disabled persons. A similar search conducted in 1981 led to many new devices that became standard products for disabled people. Now, as more people are computer literate and as the price of technology declines, it is likely that an even greater proportion of these new inventions will become commercially available in the near future.

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# A VISION OF A TOTALLY INTEGRATED LIFESTYLE

| spect | Description | Indicators |
|---|---|---|
| Education | Individualized functional curricula and experiences with students without disabilities. | -Home school placement<br>-Inclusion in regular age appropriate classes and activities<br>-Functional curriculum<br>-Community referenced training<br>-Individuals and their families integral members of the IEP planning process |
| Employment | Employment, with the necessary supports, in regular job settings. | -Individual receives transition services and has employment experiences prior to graduation<br>-Individual engages in real work in real workplace settings<br>-Individual receives support in the work environment<br>-Natural proportions of individuals with and without disabilities are employed at the work site<br>-Individual receives wages and benefits appropriate to skills and qualifications<br>-Individual communicates with peers in the work environment<br>-Individual has transportation to and from work |
| Social Relationships | Social networks and friendships throughout the individual's life. | -Individual has friends in the community<br>-Individual is included in after school and out of school activities with peers<br>-Individual has informal support network of family and friends<br>-Individual has long term, intimate relationships<br>-Individual has support in developing social relationships |
| Self-determination | Making choices that affect all aspects of lifestyle. | -Individual has opportunities to make real lifestyle choices<br>-Individual preferences are valued and acted on in lifestyle decisions<br>-Individual is involved in all aspects of lifestyle planning<br>-Individual is supported during decision making processes<br>-Individual has ability to affect lifestyle changes |
| Recreation and Leisure | Access to and membership in clubs, groups, hobbies, and cultural pursuits in the community | -Individual has choices about recreation and leisure activities<br>-Individual participates in leisure and recreation activities in the community<br>-Individual is a contributing member of clubs and groups of their choice in the community |
| Neighborhood and Community | Access to and inclusion in community activities and services. | -Individual uses neighborhood and community services on a regular basis<br>-Individual participates in neighborhood recreation and leisure activities<br>-Individual Education Plans include use of neighborhood and community services |
| Home | Appropriate living alternatives and family involvement at each stage of the life cycle. | -Participates in the selection of a place to live<br>-Individual selected a place to live among a range of options<br>-Individual selects roommates (if roommates are desired)<br>-Necessary supports were individually determined<br>-Individual is pleased with living arrangements<br>-Family is pleased with living arrangements<br>-Transition planning efforts address where a person will live<br>-Choices and desires at home are valued and respected<br>-Individual makes decisions about all aspects of home routines (decorating, meal times, vacations) |

raft discussion paper prepared by the U.S. Department of Education Office of Special Education Programs.

# SUPPLEMENTAL INFORMATION AND ACTIVITIES

## Module Four

***"For I dipped into the future,***
***Far as human eye could see,***
***Saw the Vision of the World, And***
***all the wonders that would be..."***

— Alfred, Lord Tennyson (1809-1892)

**Parents of children without disabilities are increasingly impressed with the power of individualized programs for children with disabilities, and are beginning to demand the same individualiztion for their own sons and daughters.**

***"All people are beings;***
***All humans beings are valuable;***
***All the rest is commentary..."***

– Burton Blatt - "Christmas in Purgatory"

# MIND READING COMPUTERS

## A NEW DEVICE MAY HELP "LOCKED-IN SYNDROME" PATIENTS SPEAK THEIR MINDS

Computers may soon be able to read the minds of patients suffering "locked-in syndrome"—a condition that renders them unable to communicate despite being aware of their surroundings. Locked-in syndrome may result from a coma or motor-neuron disease or other disorders, leaving the patient unable even to blink an eye.

Doctors are already able to measure brain activity using such technologies as EEGs and PET scans. Now, psychology professor C. Richard Clark of Flinders University in South Australia has developed a technique for interpreting brain-wave patterns—reading the patient's mind.

Clark and his team use an "electro-cap" to position 15 electrodes on a patient's scalp. Brain waves collected by the electrodes are then analyzed by a computer-based Artificial Neural Network, which picks up specific patterns out of noisy signals. If a patient can be taught to concentrate on a simple thought such as "yes" or "no" in response to a question, then the computer could recognize the differences in the patterns and interpret the patient's wishes.

"It's known that some people recovering from a coma have said that they were fully aware of what was going on around them but simply couldn't tell anyone, either by speech or movement," says Clark. "Similarly, motor-neuron disease sufferers are unable to voluntarily control their body movement of speech...They literally have a mind locked in a body."

Clark believes that locked-in patients can be helped as long as their brain's ability to think and originate messages is intact. "I could imagine that you could have a computer continually sampling the brain waves, looking for a particular pattern, which would indicate that a person wants something," he says. "At that stage, it would switch into a binary-split routine [e.g., 'yes' or 'no'] to home in on the area of interest, and after three or four prompts it should be possible to know exactly what the person wants."

So far, Clark's technique has achieved a 96% accuracy in measuring and interpreting the brain-wave patterns of healthy subjects. The team has just begun experiments on patients with various forms and degrees of locked-in syndrome, and while it is too soon to tell if the technique will succeed, Clark reports that "brain-wave collection from patients for assessment of the method is proceeding without a hitch."

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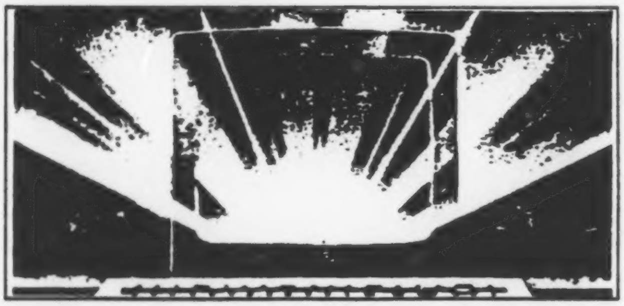

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# A CASE FOR TEACHING FUNCTIONAL SKILLS

by Preston Lewis - from December, 1987 TASH Newsletter

## My Other Brother Daryl

...is 18 years old. Has an I.Q. range of 30-40. Has been in elementary school for 12 years, never been served in any setting other than elementary school. He has had a number of years in "individual instruction." He has learned a lot of things!

Daryl can now do lots of things he couldn't do before! He can put 100 pegs in a board in less than ten minutes while in his seat with 95% accuracy. But, he can't put quarters in vending machines.

Upon command, he can touch his nose, shoulder, leg, foot, hair, and ear. He's still working on wrist, ankle, hips. But he can't blow his nose when he needs to.

He can now do a 12 piece Big Bird puzzle with 100% accuracy and color an Easter Bunny while staying in between the lines. He prefers music but was never taught how to use a radio or record player.

He can now fold primary paper in halves and even quarters. But, he can't fold his own clothes.

He can sort blocks by color, up to fifteen colors! But, he can't sort clothes: whites from colors for washing.

He can roll Play Dough and make wonderful clay snakes. But, he can't roll bread dough and cut out biscuits.

He can string beads in alternating colors and match it to a pattern on a DLM card. But, he can't lace his shoes.

He can sing his ABC's and tell me names of all the letters of the alphabet when presented on a card in upper case with 80% accuracy. But, he can't tell the men's room from the ladies room when we go out to McDonald's.

He can be told it's cloudy/rainy and take a black felt cloud and put it on the day of the week on an enlarged calendar (with assistance). But, he still goes out in the rain without a raincoat or a hat.

He can identify with 100% accuracy 100 different Peabody Picture cards by pointing! But, he can't order a hamburger by pointing to a picture or gesturing.

He can walk a balance beam frontwards, sideways, and backwards. But, he can't walk up the steps or bleachers unassisted in the gym to a basketball game.

He can count to 100 by rote memory. But, he doesn't know how many dollars it takes to pay the cashier a $2.59 coupon special.

He can put cubes in a box, under the box, beside the box, and behind the box. But, he can't find the trash bin and empty his trash in it.

He can sit in a circle with appropriate behavior and sing songs and play "Duck, Duck, Goose." But, nobody else in his neighborhood his age wants to do that.

I guess he's just not ready yet....

# TRANSPARENCIES

Module One

# John Is...

- A 28 year-old Down Syndrome
- Spastic Hemiplegic.
- SSI Receipient.
- A Behavior Problem.
- Non-Compliant to Staff Directions.
- Has Poor Personal Hygiene
- Cannot Follow Simple Three-Step Commands
- Is Severe to Profound.
- Will Need to Work on Matching and Color Skills before He can be Employed.

# John Is...

- A person who has difficulty using his right hand and arm and who needs concise and clear directions to do a good job.
- Is poorer than most people and needs a job.
- Needs a reason to take baths and wear clean clothes
- Gets angry sometimes when people tell him to do things which don't make sense to him.
- Has a difficult time explaining what he wants and needs in a way that people can understand.
- Is color blind and does not understand why he should match things.

# A DEVELOPMENTAL DISABILITY IS A:

- Mental and/or physical impairment, which;
- Starts before age 22, and;
- Continues indefinitely or for an extended period of time, and;
- Results in a functional limitation in 3 or more areas (described below), and the;
- Person needs an individually planned or coordinated combination or sequence of services.

# SEVEN MAJOR LIFE AREAS

- **Self-care** activities are the things people do daily to meet their basic life needs. They include eating, personal hygiene and grooming.
- **Receptive and expressive language** are the verbal and nonverbal skills a person needs to understand others and to express his/her ideas and feelings.
- **Learning** is the ability to acquire new behaviors, perceptions and information; the ability to apply past experiences to new situations.
- **Mobility** is the ability to move from one place to another with or without mechanical aids.
- **Self-direction** is the ability to take care of oneself; the person is able to make sound personal decisions and protect his/her self-interests.
- **Capacity for independent living** describes a person's ability to live without extraordinary support in a way that is age-appropriate.
- **Economic self-sufficiency** describes a person's capacity to maintain adequate employment and financial support.

***A functional definition focuses on how a disability interfers with a person's abilities and capacity to perform major life activities.***

*MENTAL RETARDATION refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas; communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.*

# CAUSES OF MENTAL RETARDATION

Mental retardation may stem from literally hundreds of possible causes such as:

- Genetic/chromosomal or inherited traits (Down Syndrome);
- Infections (encephalitis or meningitis), and metabolic problems (diabetes or hyperthyroidism);
- Environmental influences during pregnancy: lack of oxygen to the brain at birth, chemicals and drugs (including alcohol) ingested during pregnancy, exposure to radiation, and high temperature of a mother during early pregnancy;
- Other environmental factors (inadequate stimulation and love, or abuse, neglect, or other trauma during early childhood).

# Prenatal and Genetic Causes of Mental Retardation

Damage to the fetus before birth can result in chromosomal abnormalities. Some of the conditions that result in chromosomal damage are:

PKU: Enzymes responsible for breaking down natural bodily poisons are absent
Down Syndrome:
A chromosomal deficit
Structural Problems:
Parts of the brain or body have failed to develop properly

# Perinatal Causes of Mental Retardation

Difficulties during birth can lead to mental retardation. Some of these are:

Premature Birth
Trauma during Birth
Anoxia (lack of oxygen during birth)

# POSTNATAL CAUSES

**Postnatal causes** (after birth) such as the following can lead to mental retardation:

- **Trauma** - automobile accidents and child abuse are common causes of trauma
- **Poisons** - lead and carbon monoxide poisoning can result in mental retardation in children
- **Infections** - infections such as meningitis or encephalitis can inflame the brain or result in high fevers that can lead to mental retardation
- **Parasites** - not seen so much in this country but in other countries parasites can cause cysts or inflammation of the brain

# EPILEPSY

- **Epilepsy is a chronic brain disorder characterized by seizures.**
- **Seizures occur in approximately one to two percent of the general population but as with mental retardation, only a very small number of people with epilepsy have conditions so severe as to be classified as developmentally disabled.**
- **Although the disease itself is not inherited, recent research suggests that, in some cases, the predisposition to the disease may be a hereditary trait.**

# CEREBRAL PALSY

- **Cerebral palsy describes physical disabilities resulting from physical damage to the brain which, in turn, affects muscle coordination.**
- **These motor activities usually result from damage to the brain either before, during, or after birth.**
- **Cerebral palsy is not progressive (it does not get worse). It is not contagious. It cannot be cured.**

# AUTISM

**Autism is characterized as a disturbance in the following areas:**

- **speech and language**
- **rate of development**
- **ability to relate to people and things**
- **perception**
- **use of mannerisms**

**Individuals with autism may have difficulty in perceiving the world around them as other people perceive it. They may also has difficulty in communicating their perceptions to other individuals.**

**It is a sad commentary that parents, especially mothers, have had a long history of being unfairly blamed by professionals for their child's disability.**

The National Organization on Disability produces the following national statistics, (Please remember that the following information is based on all disabilities, regardless of severity or age of onset):

- 43 million Americans have some type of physical or mental disability (17 percent of total population).
- 22 million Americans are hearing impaired; 2 million are deaf.
- 2.5 million are severely visually impaired, while 120,000 are totally blind and 600,000 are legally blind.
- For all age groups, females report higher percentages of physical functional limitations than do males.
- 2 million people with disabilities live in institutions, including nursing homes, mental hospitals, residential facilities and mental retardation facilities. Over 1.3 million are in nursing homes.
- On average, people with disabilities have less education, less income, fewer job opportunities and fewer social contacts than others.
- 8.2 million working aged adults with disabilities were unemployed at the beginning of 1990. People with disabilities are the most welfare dependent minority in the U.S.
- More than 46 percent of all people over 65 have some type of disability.
- More than 25 million people with disabilities are registered voters.
- There are approximately 177,000 Americans with Spinal Cord Injury.

# TRANSPARENCIES

## Module Two

# HISTORICAL OUTLINE

| | |
|---|---|
| **1790 -- 1850** | **Positive attitudes** |
| **1850 -- 1890** | **"We Need To Protect Them"** |
| **1890 -- 1910** | **Backlash organized against people who are seen as "different."** |
| **1910 -- 1930-40's** | **Negative images persist.** |
| **1940-50's--1950's, early 60's** | **Parent groups begin** |
| **Mid 60's -- Mid 70's** | **Parents agitate. Institution exposes** |
| **1970's -- 1980's** | **The result of the previous events:**<br>**1) More resources flowed into institutions**<br>**2) Resources didn't solve problems.**<br>**3) Start of new community services** |
| | **The above three events occurred simultaneously** |
| **Late 70's -- early 80's** | **1) Improvements in institutions.**<br>**2) Excitement about community programs.**<br>**• Institutional returnees "blossoming."**<br>**• Families glad to have people back in their own communities.**<br>**• Success stories concerning jobs, schools, places to live, etc.**<br>**• Community agencies becoming more skilled** |

# HISTORICAL ROLE PERCEPTIONS

As seen from the historical overview, throughout history society has developed certain perceptions of individuals with disabilities. Some of these are discussed in the following section.

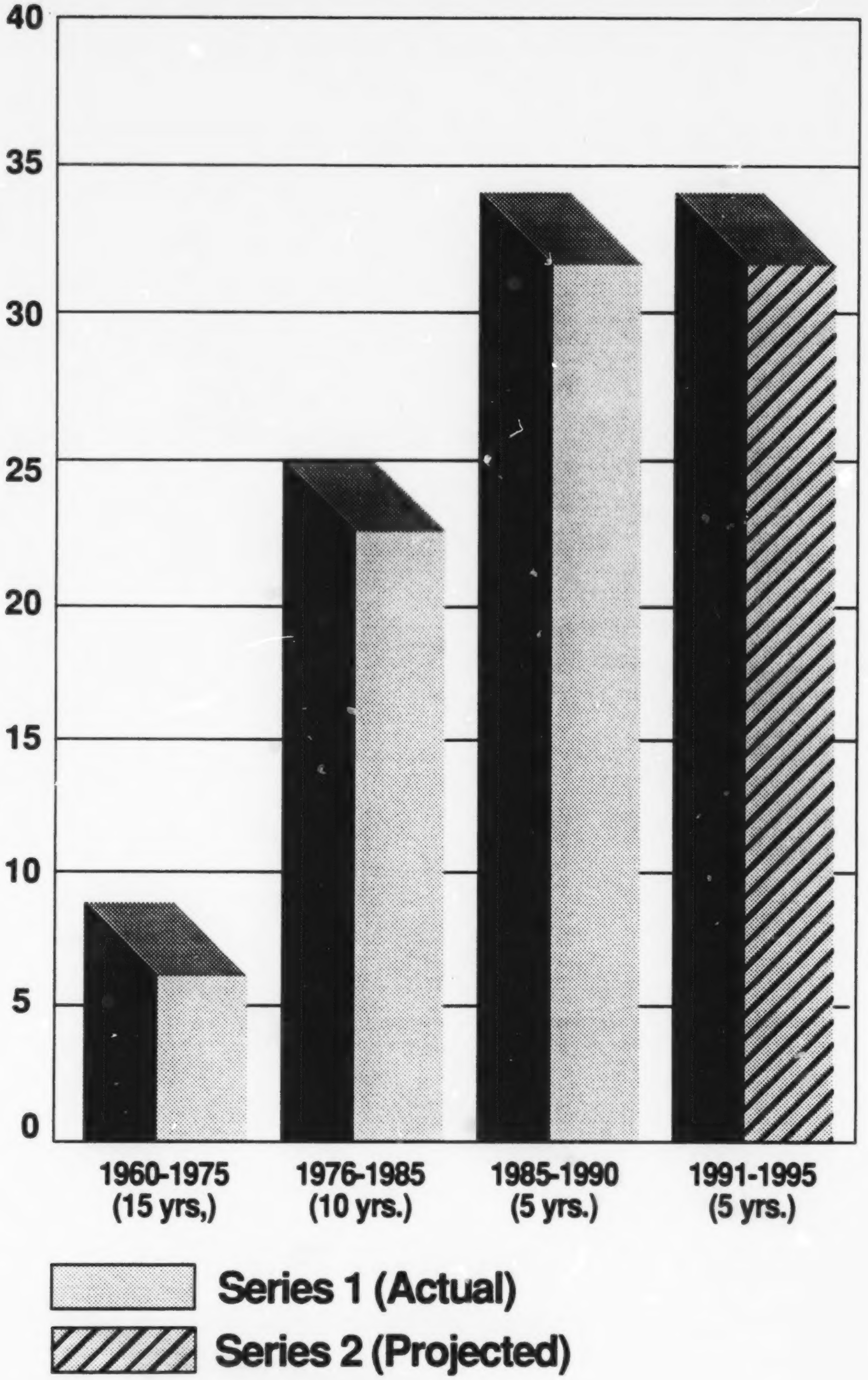
- SUBHUMAN ORGANISM
- OBJECT OF PITY
- OBJECT OF RIDICULE
- UNSPEAKABLE OBJECTS OF DREAD
- HOLY INNOCENTS
- ETERNAL CHILD
- SICK PERSON
- MENACE TO SOCIETY
- OBJECT OF CHARITY

# OTHER MISCONCEPTIONS HISTORICALLY PERPETUATED

Certain beliefs and misconceptions about people with developmental disabilities have been, and still are, commonly found in our society. The following misconceptions have been historically perpetuated.

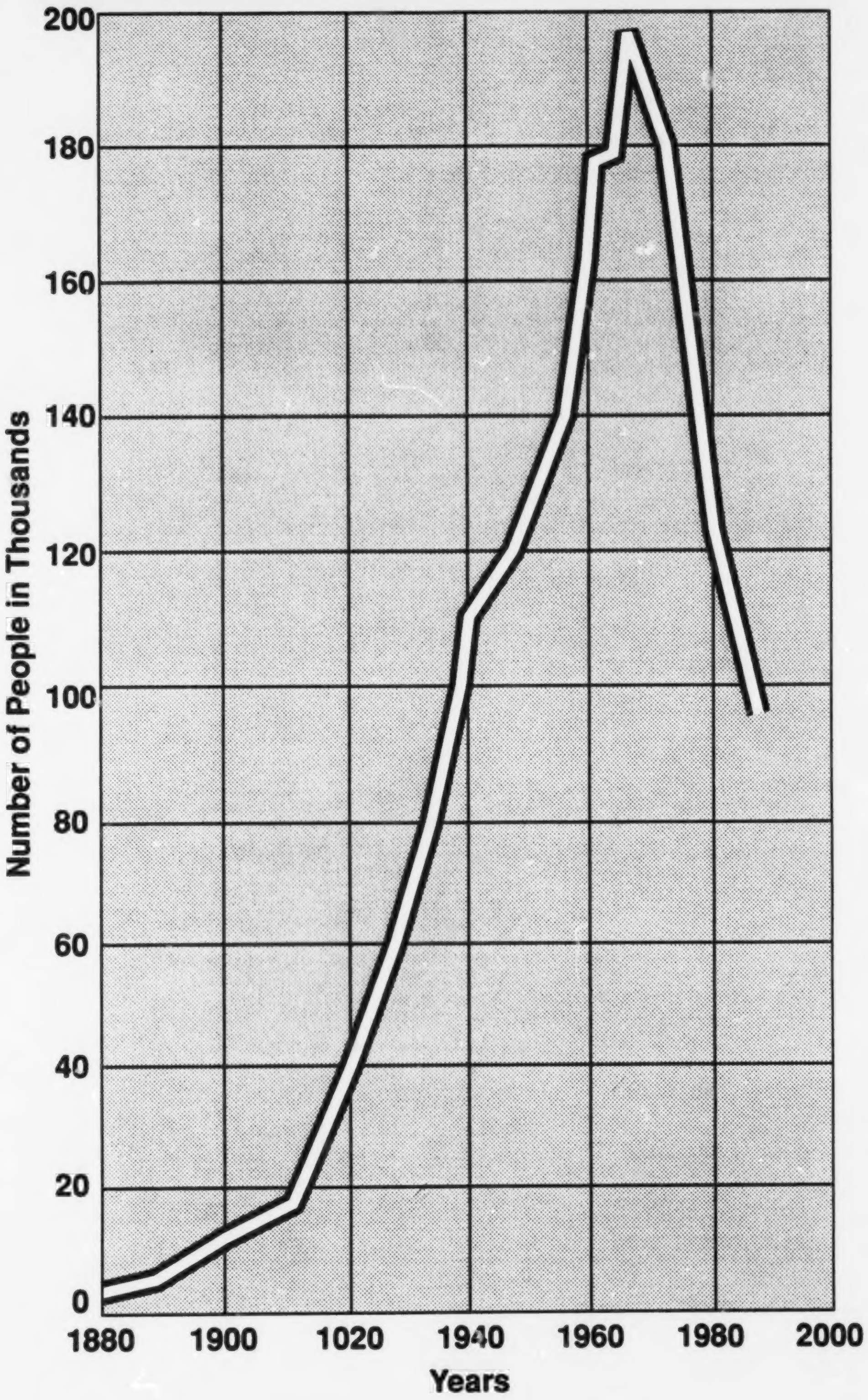
- A Life of Complete Dependency
- Mental Retardation Equals Mental Illness
- All People with Mental Retardation Act Alike
- A Person Can Function to the Extent of his/her Mental Age or IQ
- People with Developmental Disabilities should have "Special" Environments

## U.S. Closures & Projected Closures of State Institutions – Persons with MR/DD



*Population: 220,000 Peak*
*65,000 Currently*

**Total Number of Persons with Mental Retardation in U.S. Public Institutions**



# ARGUMENTS ON WHY CONGREGATION HAS NOT WORKED

- If you put people into groups, you subordinate individualization for the greater good of the whole.
- Imitation and role modeling are powerful learning tools.
- Absence does not make the heart grow fonder.
- Skills need to be taught in the environments where they will be used.
- "Special" often isn't. "Pre" means never.
- Bigger isn't better or cheaper.
- Lack of contact

***Lack of contact =***
***Lack of knowledge =***
***Fear of the unknown =***
***Justification for distancing (Us/them)***

## SEGREGATION REINFORCES...

Segregation reinforces the belief in others that those who are segregated **need** to be segregated; they benefit from it.

**It reinforces fear of people with developmental needs,** and the belief, that **if society has seen fit to put these people away, it must be for a good reason -- they must represent some type of threat**.

We cannot form an objective opinion of them. Lack of understanding gradually metamorphoses into a belief that they must be menacing or unsociable.

# Legislation

## A BRIEF OVERVIEW AND DISCUSSION OF LEGISLATION

### REHABILITATION ACT (1973)

Section 504 of the **Rehabilitation Act** (1973) was the first civil rights law which guaranteed equal opportunity for more than 35 million Americans with disabilities.

The language of the law is similar to that in other civil rights acts which prohibit discrimination.

# INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

### (Public Law 94-142)

**This law was formerly called the Education for the Handicapped Act.**

**Appropriate implementation of the Individuals with Disabilities Education Act will ensure that the history of exclusion and neglect shown by public schools will not be perpetuated.**

# DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

**Developmental Disabilities Assistance and Bill of Rights Act established a federally assisted state program designed:**

- To enhance the role of the family in assisting people with developmental disabilities to achieve their maximum potential;
- To provide interdisciplinary training and technical assistance to professionals, paraprofessionals, family members, and individuals with developmental disabilities;
- To advocate for public policy change and community acceptance of all people with developmental disabilities and their families so that the necessary services, supports, and other assistance and opportunities are available;
- To promote the inclusion of all people with developmental disabilities;
- To promote the interdependent activity of all people with developmental disabilities;
- To recognize the contribution of all people with developmental disabilities as they share their talents at home, school, and work, and in recreation and leisure time; and
- To ensure the protection of the legal and human rights of people with developmental disabilities. (Section 102(b))

# MISTREATMENT/MALTREATMENT

Mistreatment results in, or creates the risk of, injury of a child or resident including (but not limited to) the following situations:

1. Conduct which evidences a reckless disregard for the health or safety of a child or resident.

2. Acts or omissions which contribute to the delinquency of a child.

3. Excessive or unauthorized use of force.

# PHYSICAL ABUSE

**Some examples of physical abuse are:**

- Hitting, shoving, tripping, pushing, scratching, cutting, biting, etc.
- Using physical or chemical restraints

**Some signs of physical abuse are:**

- bruises and welts
- cuts, punctures, scratches
- broken bones and fractures
- burns
- human bite marks
- internal injuries
- suspicious scars
- unexplained fear of caregiver
- unexplained injuries or injuries that do not “add up”

# SEXUAL ABUSE

**Some signs of sexual abuse may be:**

- behavioral changes
- recurrent nightmares, night fears
- infantile behavior
- unusual interest in or knowledge about sexual matters
- self-destructive behavior
- overheard sexual remarks concerning rape or abuse

**Physical signs may include:**

- torn or stained underclothing
- vaginal or rectal bleeding, pain, itching or swollen genitals, vaginal discharge
- vaginal infection or disease

# EMOTIONAL ABUSE

## Examples of emotional neglect and abuse may include:

- Constant negative atmosphere
- Extreme teasing or humiliation
- Talking down to the individual
- Threatening with physical harm
- Withholding emotional support

## Signs of emotional abuse may include:

- changes in behavior
- expression of fears
- expression of suspicion
- unwillingness to talk

# EXPLOITATION

The term "Exploitation" means the unjust or improper use of the personal resources of a person for the profit or advantage, pecuniary or otherwise, of another person. Exploitation includes but is not limited to prohibited business transactions such as follows:

- Buying or selling any item or items for money or items of trade to clients
- Trading articles by force from a client
- Taking any article by force or stealing from a client
- Bartering with a client for articles or money
- Borrowing money or any item of value from a client
- Accepting articles in the form of a gift from client

# NEGLECT

## Examples of neglect may be:

- Insufficient diet
- Insufficient opportunity for personal hygiene
- Inadequate shelter
- Medical neglect
- Inadequate supervision

## Some signs of neglect may be:

- provider has an alcohol or drug problem
- individual is fearful of a provider
- health problems
- dehydration
- decubiti

# GENERAL RULES FOR PREVENTING MISTREATMENT

**Wise care givers take precautions to prevent situations that may lead to mistreatment occurring. Some of these are;**

- Treat all people with dignity and respect.
- Do not make verbal threats. Words can turn into actions.
- Call for help if you are in doubt about how to handle a client or situation.
- Admit when you have made a mistake. The people you serve can be right about issues, just as you can be right.
- Get enough sleep so you are alert on the job and so your patience will remain intact.
- Never drink alcohol or use tranquilizing or stimulating drugs before coming to work.
- Be careful what you wear; don't let your clothes give off sexual messages.
- Don't be so preoccupied with orderliness and good behavior that control and authority are the only means used to teach clients appropriate behavior.
- Most importantly!!! Send a clear message to those around you that you will report mistreatment.

# VALUES

- We value being recognized as individuals, separate from any class label.
- We value being accepted by friends, neighbors and sales people as OK.
- We value living with people we love. A comfortable home. Good neighbors.
- We value having the opportunity to make choices and not being limited to one job, or one outfit, or one TV show.
- We value doing things for ourselves. Being as independent as possible.
- We value making our own decisions and knowing the joy of being right, or even being wrong, if we can learn from it.
- We value being respected for doing a job well, being considered competent.
- We value having friends who enjoy our company so we have the option of being included socially. To take in a Saturday night movie with the gang is a lot of fun. So is shooting the breeze during a card game.

# What We Can Do About Social Integration

Here are a few hints about what we can do to foster full social integration:

- ☞ Encourage the mixing and interaction of people having developmental disabilities with ordinary people their own age in all areas of life.

- ☞ Demonstrate that integrated classes and job training are better growing and learning environments than segregated settings. Remember that "Pre" means "never":
  "Pre-Vocational"
  "Pre-Educational"
  "Pre-Living"

- ☞ Do your best to ensure that people with developmental disabilities dress, act, and are seen in ways which don't make them appear odd.

- ☞ Insist that different groups with different needs be served in different places. Congregating large numbers of people with differing needs tends to transfer erroneous or negative images from one group to the other. It also tends to promote destructive competition for available staff resources and training opportunities.

## WHAT HAVE WE LEARNED?

## HERE ARE A FEW TIPS TO KEEP IN MIND:

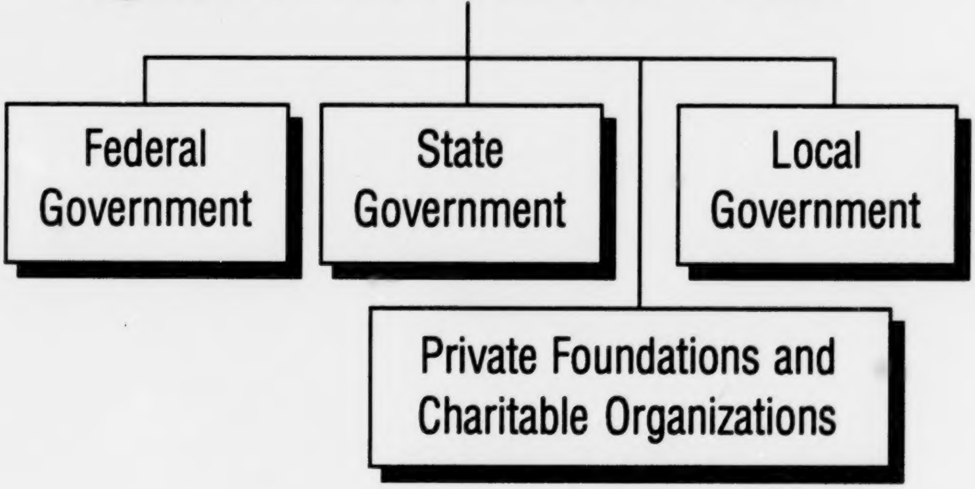
- Where you live says a lot about who you are and how you are viewed by yourself or others. A home that looks "down and out" with a lawn that hasn't been mowed or paint peeling from the walls says the people who live there don't care and don't matter.
- A home should be in a residential neighborhood and should be an easy walk to shopping, recreation, and public transportation resources. It should be in the middle of things.
- Don't give a home an official name. You can't improve on the street address. Signs on the door only clang.
- Homes should fit in with their surrounding neighborhoods as much as possible.
- Living arrangements for people with developmental disabilities should be highly dispersed and not in zoning ghettos.
- A home should feel and look warm, be decorated thoughtfully and age appropriately.
- People with disabilities should be helped to dress in ways that are typical for their age. Adults should not wear childlike clothing. School-age children and teenagers should look like all other kids their own age.

# TRANSPARENCIES

## Module Three

# OKLAHOMA SERVICE SYSTEM

## *Agencies that Provide Funds*



Federal Government

State Government

Local Government

Private Foundations and Charitable Organizations

# THE FEDERAL GOVERNMENT

## I. Health and Human Services

A. Social Security Administration

B. Health Care Financing Administration

## II. U.S. Department of Housing and Urban Development (HUD)

A. Direct Loans for Housing for People Who are Elderly or Handicapped

B. Rental Rehabilitation Program

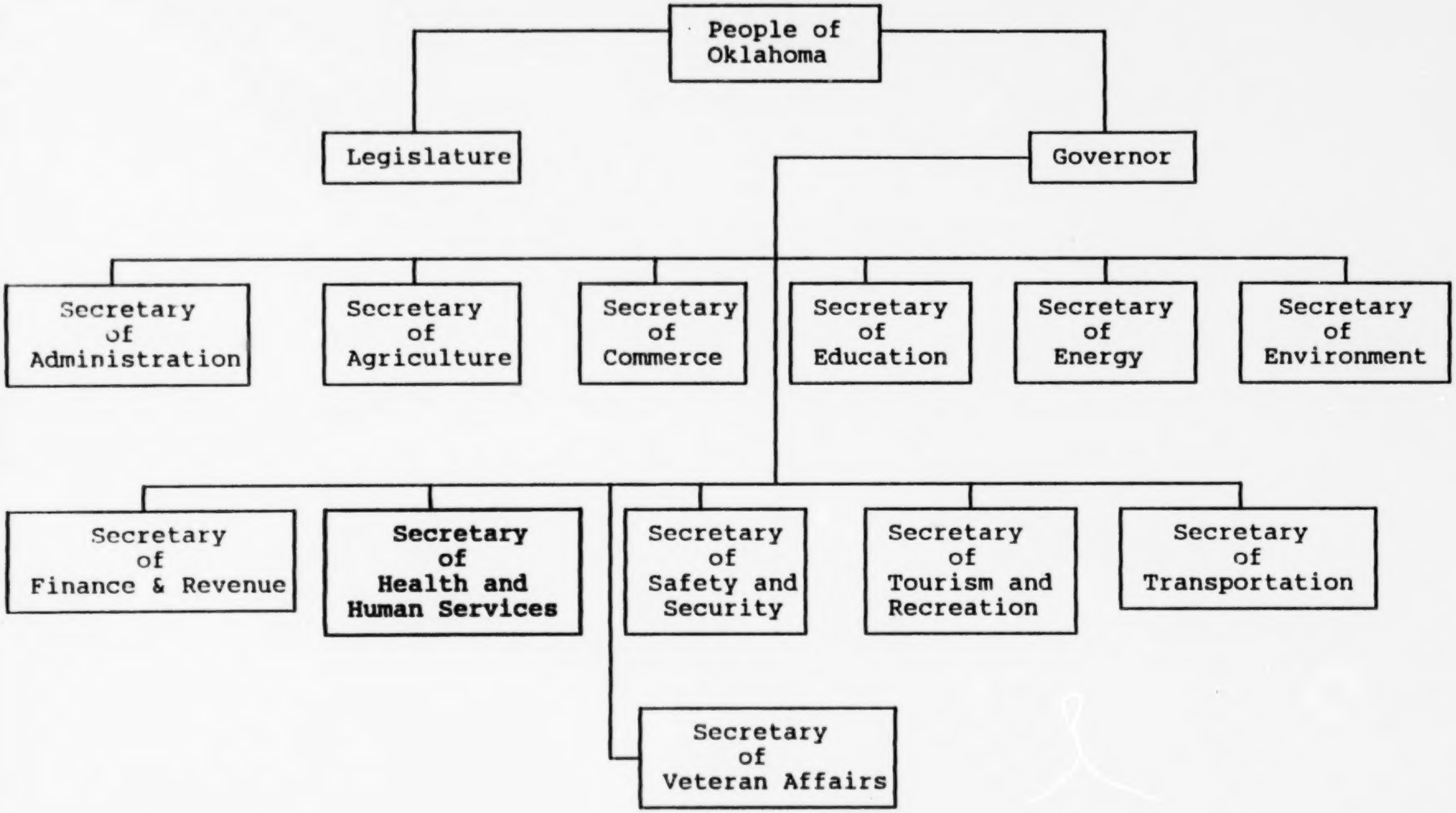
C. Supportive Housing Demonstration Program, Permanent Housing Component

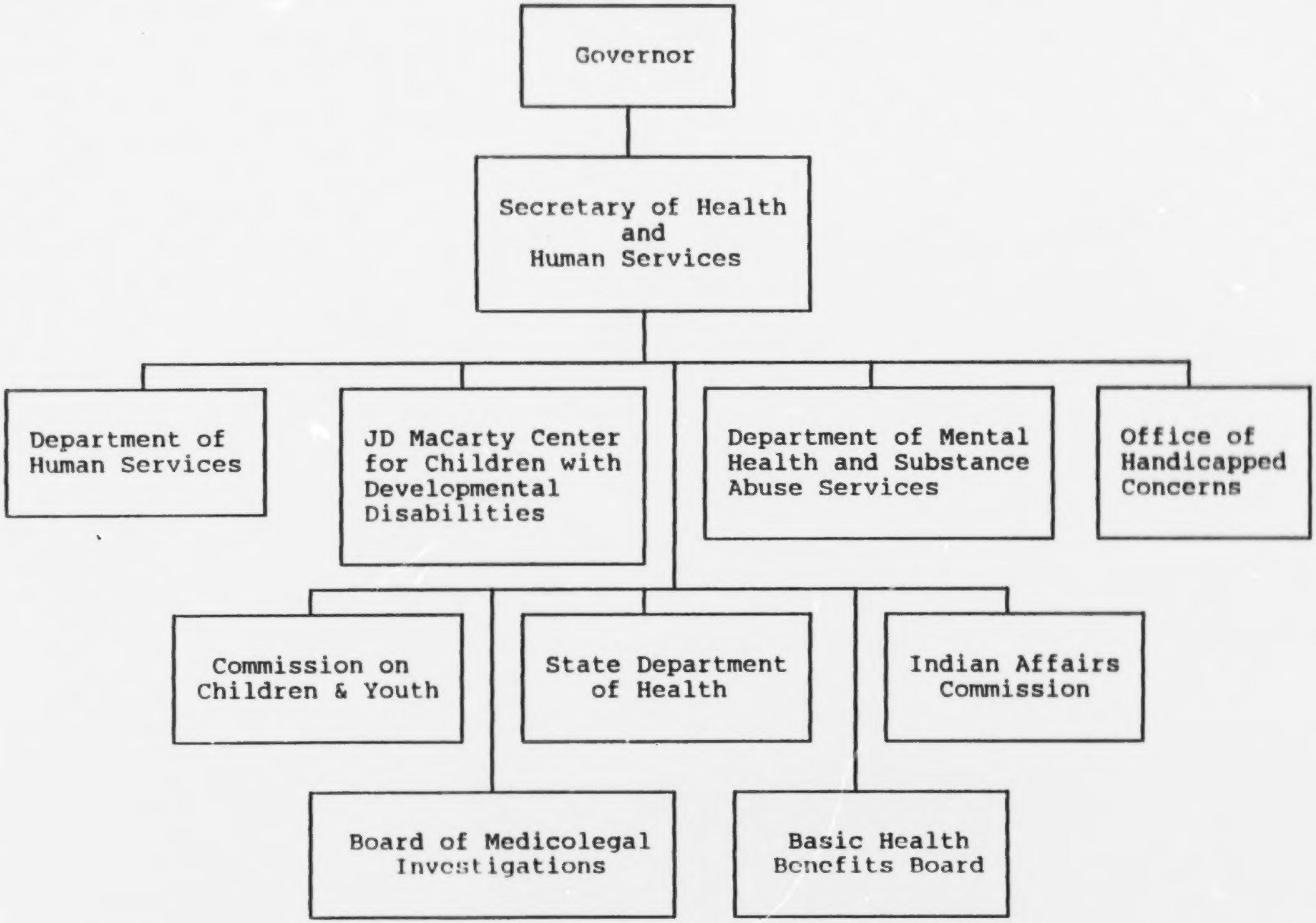
D. Community Development Block Grants

# STATE DEPARTMENTS PROVIDING SERVICES

**Oklahoma state agencies providing services:**

- **Oklahoma Department of Human Services**
- **Oklahoma Department of Education**
- **Oklahoma Department of Health**
- **Oklahoma Department of Mental Health and Substance Abuse**
- **Oklahoma Commission on Children and Youth**


People of Oklahoma
Legislature
Governor
Secretary of Administration
Secretary of Agriculture
Secretary of Commerce
Secretary of Education
Secretary of Energy
Secretary of Environment
Secretary of Finance & Revenue
**Secretary of Health and Human Services**
Secretary of Safety and Security
Secretary of Tourism and Recreation
Secretary of Transportation
Secretary of Veteran Affairs


Governor
Secretary of Health and Human Services
Department of Human Services
JD MaCarty Center for Children with Developmental Disabilities
Department of Mental Health and Substance Abuse Services
Office of Handicapped Concerns
Commission on Children & Youth
State Department of Health
Indian Affairs Commission
Board of Medicolegal Investigations
Basic Health Benefits Board

# I. OKLAHOMA DEPARTMENT OF HUMAN SERVICES

## ■ DEVELOPMENTAL DISABILITIES SERVICES DIVISION

## ■ REHABILITATION SERVICES DIVISION (RSD)

**Rehabilitation and Visual Services**

**Supported Employment**

**Rehabilitation Teaching Services**

**Schools for the Blind and Deaf**

**Other Services**

- Interpreter services
- Library for the Blind and Physically Handicapped
- Orientation and Mobility Specialists
- Deaf/Blindness and Aging Specialists
- Independent Living Programs
- Transitional Living Centers

## MEDICAL SERVICES

Medicaid

EPSDT (Early and Periodic Screening, Diagnosis and Treatment)

Children with Special Needs (Formerly Crippled Children's Program)

SSI - Disabled Children's Program

Child Welfare

## OTHER FREQUENTLY USED SERVICES

Non-Technical Medical Care

Home Maintenance Aide Services

Food Stamps and Energy Assistance

Payment for day care, AFDC, or any of the other services provided under the DHS umbrella

## II. STATE DEPARTMENT OF EDUCATION

- Provides services at the district level
- Shapes policy, monitors quality of programs, provides training and techical assistance
- Monitors compliance with federal programs and coordinates in-school programs

## III. THE STATE DEPARTMENT OF HEALTH

The focus of the State Department of Health (SDH), as well as local health departments, is the prevention of disease, illness, accidents, disabilities, and other health problems.

- Newborn hearing screening
- Genetic counseling clinics
- Residential licensing
- Education in human sexuality
- Child abuse prevention services

## IV. DEPARTMENT OF MENTAL HEALTH AND SUBSTANCE ABUSE

## VI. OKLAHOMA COMMISSION ON CHILDREN AND YOUTH

# ADVOCACY

**Advocacy is acting on behalf of another person.**

- An Advocate may be a friend, a parent or foster parent, a lawyer, a guardian, a teacher, or a social worker who takes specific action to defend the rights and interests of their loved one, student, or client.

- The degree of involvement may include:

(a) insuring due process or having a right enforced;
(b) engaging in a compensatory justice of making things equal for all; or
(c) correcting measures which are aimed at making up for previous disadvantages the group or individua has suffered.

- Some of the advocacy groups in Oklahoma are:

United Cerebral Palsy
Epilepsy Foundation
Autism Society
Office of the Guardian Ad Litem
Office of Client Advocacy
People First of Oklahoma

# ADVOCACY GROUPS IN OKLAHOMA

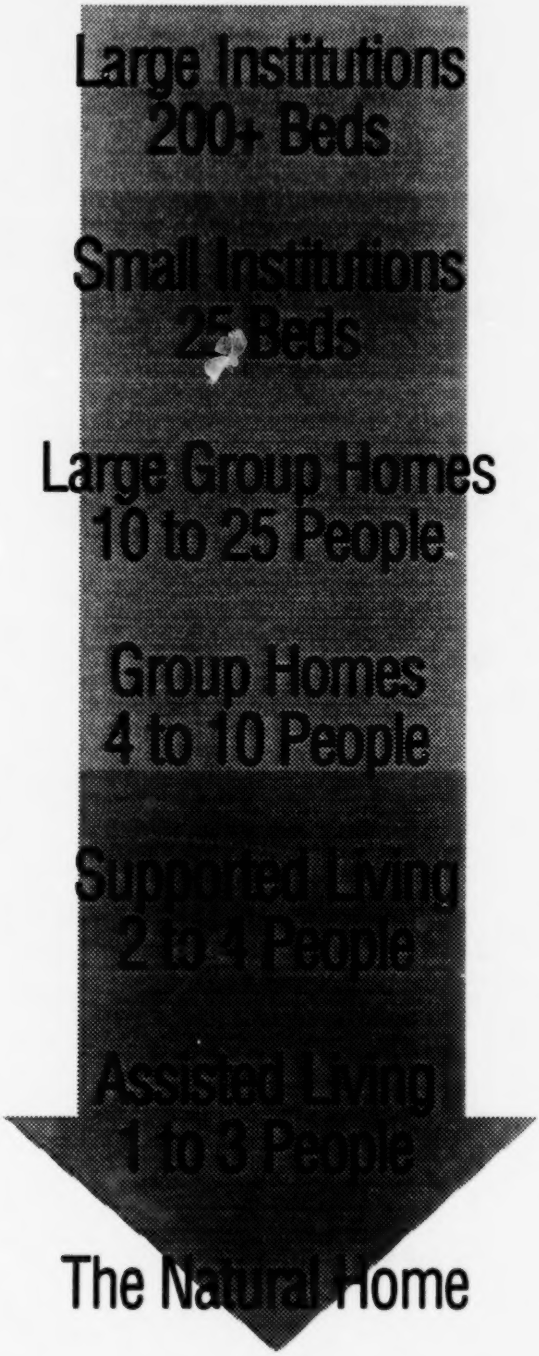
## ■ GOVERNMENT ADVOCACY GROUPS

**OFFICE OF CLIENT ADVOCACY (OCA)**
**THE OKLAHOMA PLANNING COUNCIL FOR DEVELOPMENTAL DISABILITIES**
**THE OKLAHOMA DISABILITY LAW CENTER**
**UNIVERSITY AFFILIATED PROGRAM OF OKLAHOMA (UAP)**
**OKLAHOMA OFFICE OF HANDICAPPED CONCERNS (OHC)**
**OFFICE OF THE GUARDIAN AD LITEM**

## ■ PRIVATE ADVOCACY GROUPS

**OKLAHOMA COMMUNITY PROVIDERS (OCP)**
**PRO-OKLAHOMA (Parents Reaching Out in Oklahoma)**
**POSITIVE REFLECTIONS**
**THE TULSA ASSOCIATION FOR RETARDED CITIZENS (TArc)**
**OKLAHOMA PEOPLE FIRST**

## *Most Restrictive*



Large Institutions
200+ Beds

Small Institutions
25 Beds

Large Group Homes
10 to 25 People

Group Homes
4 to 10 People

Supported Living
2 to 4 People

Assisted Living
1 to 3 People

The Natural Home

## *Least Restrictive*

EST COPY AVAILABL

# THE SERVICES PROVIDED

**In-Home Services include:**

1. Respite (in and out of home)
2. Meals on Wheels - for adults with very severe handicaps who live in their own homes
3. Architectural Modification - for accessibility
4. Visiting Nurse
5. Community Recreation
6. Professional Support - psychologists, physical therapists, speech therapists, occupational therapists, etc.
7. Transportation
8. Habilitation Staff - personnel funded by Title XIX to provide training and support as needed to the person with developmental disabilities in the home
9. Supported Living - 1-3 persons managed by a provider whose lease on their home may be in their own name
10. Assisted Living

**Out-Of-Home Services provided include:**

1. Group Homes - 4-15 individuals
2. Institutions - resource centers
3. Nursing Homes
4. Private ICFs/MR - institutions
5. Foster Care
6. Adult Companion (may be in own home or companion's home)

**Services shared by both In-Home and Out-of-Home**

1. Respite
2. Architectural Modification
3. Visiting Nurse
4. Community Recreation
5. Professional Support
6. Transportation

# TYPES OF RESIDENTIAL SERVICES

- Assisted Living
- Supported living
- Habilitation Services
- Adult Companion
- Foster Care
- Group Home
- Resource Centers
- Nursing Homes (ICF's, ICFs/MR)

# VOCATIONAL SERVICES

**Vocational services** are those services which assist the individual to engage in employment or employment-related activities during the day.

- **Integrated Employment**
- **Sheltered Employment**

# CASE MANAGEMENT

- **Case Managers** make sure that the person they serve gets everything they need and are entitled to.
- **Above all, the case manager is a friend that can be counted upon in time of need.**

# SUPPORT SERVICES

**Support Services** are those professional, therapeutic, and habilitation activities which maintain or enhance an individual's physical, emotional, and social well-being in the community. Support services are categorized into five general areas:

- **ASSESSMENT SERVICES**

- **COMMUNICATION SERVICES**

- **SKILL DEVELOPMENT SERVICES**

- **BEHAVIORAL SUPPORT SERVICES**

- **HEALTH CARE SERVICES**
  - **Skilled Nursing Services**
  - **Dental Services**
  - **Nutritional Services**
  - **Psychiatric Services**
  - **Hearing Treatment**

- **ACCESSIBILITY**
  - **Architectural Modifications**
  - **Assistive Technology**
  - **Mobility Services**
  - **Transportation**

# ELEMENTS OF A GOOD PROGRAM

- A "WORKING" PROGRAM
- MAXIMUM CHALLENGE
- RISK-TAKING
- MEASURING RESULTS
- GOOD PROGRAMS COME FROM GOOD STAFFS
- WE ARE THE LEARNERS

# DEVELOPING THE INDIVIDUAL PLAN

Planning works best when a team of individuals work together -- each one contributing knowledge or expertise in a particular area so that the individual's plan will consider all the person's strengths and needs.

3 Phases:

- The "**PLANNING PHASE**"
- The "**INMPLEMENTATION PHASE**"
- The "**MONITORING PHASE**"

**The IHP has limitations:**

- we cannot anticipate all that might happen in a person's life.
- it is not a substitute for competence;
- a plan written for one setting will not always transfer to another setting.

# TRANSPARENCIES

## Module Four

# STATEMENT OF BELIEFS

We, the people of Oklahoma, with a firm belief in the inalienable rights of all individuals to live full lives, do state:

- All individuals have the right to lead productive lives to the fullest extent possible;
- All individuals have the right to full participation in the decisions that concern their lives;
- All individuals have the right to be educated to the highest degree, and in the most typical environment, possible;
- All individuals have the right to their personal values without imposition or infringement;
- All individuals have the right to fully exercise their liberties as citizens of their community and country;
- All families are entitled to the integrity and well-being that comes from the firm assurance of support and entitlement;
- All individuals have the right to risk; to experience not only the satisfaction of achievement, but also the challenges of failure;
- All individuals should have their needs respected with regard for individual desires, capabilities, living situations, and medica requirements.

# POWER OF SELF-ADVOCACY

Individuals with developmental disabilities must recognize their own worth. They must be able to come to the realization that they have the power of self-advocacy — the power to influence their own futures.

As a population, they can bring about changes in attitudes and beliefs by their very participation in community and national affairs.

# *SUPPORT!*
# *NOT SUPPLANT*
# ***the natural home***

# MATRIX

***What has been in the Past → Future***

| | | | | |
|---|---|---|---|---|
| Physical and Social Exclusion | → | Physical and Social Presence | → | Physical and Social Presence and Participation |
| **(SEGREGATION)** | → | **(INTEGRATION)** | → | **(INCLUSION)** |
| **EDUCATIONAL** | | | | |
| Separate School Buildings | → | Separate Classrooms | → | Supporting in Same Classroom |
| **RESIDENTIAL** | | | | |
| Large Institutions | → | Small Institutions<br>Group Homes | → | Home Owner<br>Natural Home |
| **VOCATIONAL** | | | | |
| Workshops/<br>“Activity” Centers | → | Work Crews<br>Enclaves in Industry | → | Real Jobs in Real Places |

**Some technological devices that may be in common use in the future include:**

- Hovercraft (wheel)chairs that will allow movement over the most rugged surfaces.
- Telephone accessory devices that relay typed messages from individuals with hearing impairments to other telephone users.
- Computer-controlled doors that respond to voice commands to open and shut.
- Glasses that allow people with hearing impairments to read what a speaker is saying on the inside of the lens.
- Talk-back computers that allow individualized education as well as open employment opportunities in a variety of fields.

**Devices that are readily available include the following:**

- Chairlifts that allow individuals to get in and out of bathtubs.
- Battery-powered, light aluminum and plastic chairs to replace heavy steel wheelchairs.
- Flexible and miniaturized communication boards and computer keyboards that allow communication of needs and feelings.

# Our Task

- Our task each day is to give the assistance required to allow each individual to be as independent as possible.

- Our task each day is to be an advocate who helps create the work, leisure and home environment which allows each individual to be as independent as possible.

- Our task each day is to treat the people we serve with respect and dignity. Regardless of their developmental disability, each person deserves the opportunity to live the fullest life possible.

- Our task each day is to provide the resources necessary for each individual to accomplish the fullest life possible.